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Plenary Sessions

PL1.1. New medicines for Alzheimer’s disease: Lessons from past failures and perspectives for the future

WINBLAD Bengt

In 2010, the number of people affected by dementia worldwide was estimated to 36 million, with an estimated cost of approx 600 bUSD. The prevalence of dementia is expected to reach 115 million in 2050, with an equivalent cost increase. The progressive nature of dementia influences the whole life situation for families during several years-decades and so far, no cure or highly significant symptom relieving treatment is available. Increased understanding of the pathophysiology of Alzheimer disease (AD) has given us new therapeutic targets, and by using new biomarkers possibilities to diagnose patients earlier. Many clinical and experimental studies are ongoing, mainly based on anti-amyloid-beta (A\beta) strategies, but the exact role played by A\beta in AD pathogenesis is not yet clear. We need to acknowledge that a single cure for AD is unlikely to be found and that the approach to drug development for this disorder needs to be reconsidered. Preclinical research is constantly providing us with new information of the complex AD puzzle, and an analysis of this information might reveal patterns of pharmacological interactions instead of single potential drug targets.

Since the last drug entered the market in 2002, many products in different development phases have failed. Why? Wrong molecules, inappropriate animal models, insufficient proof-of-concept studies, heterogeneous patient groups, too advanced disease, non-relevant outcome measures, intercenter variability in increasingly globalised multi-centre trials?

Our hope for the future is that new therapies could potentially slow or even halt the progression of the disease. Increased global collaboration between academia, industry and regulatory authorities is a vital step for a successful drug development.

We have good hope that until 2025, ongoing studies directed towards beta-amyloid and/or tau metabolisms have proven effective and are on the market. Recently positive reports have been presented regarding passive immunotherapy and inhibition of beta-amyloid production.

PL1.2. Improving the timely diagnosis and providing adequate support to people with early memory complaints

PASQUIER Florence

Memory disorders are one of the most distressing symptoms with ageing. Alzheimer’s disease is famous and feared. However people are not all alike. Some worry quickly and want to know and understand what happens to them. Others reassure themselves, attribute their problem to inconvenience of age, or do not want to know, and temporize. Then will come the time when memory problems are so severe that the persons will forget that they forget and deny their troubles up to refuse assistance and support. This is not easy for the entourage. Many studies show the advantages of an early diagnosis for the patient: relief to understand what is going on, proper care, and appropriate attitude of the close relatives, increased empowerment... And now, innovative therapies are tested in people at risk for developing Alzheimer’s disease because of the presence of lesions associated with this disease in their brain, before any symptoms. Surveys have shown that most people say they want to know if they will develop Alzheimer’s disease, but much less will follow the process when the opportunity arises. A too early diagnosis may communicate uncertainty. On the other hand, a timely diagnosis refers to the subjective experience of the disease, and meets the concerns of the patients and their close relatives. Recommendations guide the diagnosis disclosure process, and help breaking bad news. The diagnostic process, like the disclosure itself, has a time frame. It is useful to know what are the patients’ knowledge and thoughts regarding both their current symptoms and their possible causes. It allows to correct erroneous beliefs and to personalize the disclosure. The process should not be too long, nonetheless its duration permits the patients to progress in their relation with the disease and diminish the brutality of the disclosure situation.

PL1.3. From biomarkers to clinical trials – big data and public-private consortia for Alzheimer’s disease prevention

LOVESTONE Simon

Despite increasing knowledge and understanding of the mechanisms of Alzheimer’s disease and related dementias generated in academia, and the considerable efforts of the pharmaceutical industry to develop therapies, we are all only too conscious of the repeated failure of drug trials at late stage. This is enormously costly to the companies who for the most part fund such trials, to the health services and even economies of all of our countries but most of all to those with dementia today and who will suffer from dementia tomorrow in the absence of a therapy for disease modification. It is not clear why the trials are failing. Is it because we have only an incomplete understanding of the condition? Is it that the trials are conducted too late in the disease process? Or is it simply that the drugs don’t work well enough? Clearly no one truly knows the answer to this but what is overwhelmingly clear is that this is a very hard problem and hard problems tend to require new solutions. It isn’t enough to continue to do the same thing.

One potential, and partial, solution to the hard problem of Alzheimer’s disease is the innovative use of data and another is public private partnerships. Neither are truly novel but arguably neither have been used to quite the same degree as is being implemented by two Innovative Medicine Initiatives (IMI) – the European Medical Information Framework (EMIF) and the European Prevention of Alzheimer’s Disease studies (EPAD). These large, pre-competitive public private consortia bring together university and other public and third sector organizations together with many large pharma and small biotech and other companies. EMIF is focused on the re-utilisation and aggregation of data and cohorts for dementia...
PL1.4. Prevention of Alzheimer’s disease – Myths, wishes and reality

PIRTOŠEK Zvezdan

Because Alzheimer’s disease (AD) is such a devastating disease, many unproven and unscientific prevention strategies are advised and patients may be tempted by untried, unproven, and unscientific treatments. Risk factors can be divided into two groups: those that can not be controlled and those which can be influenced by certain health, lifestyle and environmental factors.

1. Risk factors for AD that are beyond our control include age and genetics. The risk of developing the disease doubles every 5 years over age 65 and it is estimated that up to half the people older than 85 have AD. Genetic link to two forms of AD has been found: (i) early onset AD (before the age of 65) is associated with changes in certain genes on three chromosomes; (ii) risk of late onset AD (after the age of 65 y) is increased with the APOE \(\varepsilon\)4 form of the APOE gene, while the APOE \(\varepsilon\)2 form of this gene may provide some protection.

2. However, a number of health, lifestyle, and environmental factors may help lowering the chances of developing AD: (i) factors modifying cardio-vascular risks (e.g. controlling levels of cholesterol with diet or drugs – statins, controlling levels of homocystein by increasing intake of folic acids and vitamins B6 and B12); (ii) lowering high blood pressure levels; (iii) controlling diabetes and insulin resistance (treatment with rosiglitazone); (iv) mechanisms of inflammation and antiinflammatory drugs; (v) antioxidant mechanisms (vitamins E, C, selenium); (vi) estrogen-related mechanisms; (vii) immunization as a possible preventive strategy; (viii) exercising regularly; (ix) engaging in social and intellectually stimulating activities.

For the time being, it is not possible, unfortunately, to prevent or even delay AD. However, ongoing studies (overviewed in the talk) clearly suggest that certain lifestyle activities and substances might reduce the effect of possible AD risk factors.

PL2.1. A New European Joint Action

HUGGINS Geoff

The session will describe the objectives and structure of the new joint action on dementia and how it builds on the previous work taken forward under Alcove. The focus of the joint action is diagnosis and support, care co-ordination, the quality of residential care for those living with dementia and the development of dementia friendly communities. In terms of approach the joint action will have a clear focus on implementation as well as evidence of best practice and will work to accelerate the uptake of best practice.

PL2.2. A positive impact of collaboration in the Joint Programme on Neurodegenerative Diseases Research (JPND) on the National Research Policy

VOLASKO Peter

JPND is relatively well-known and appreciated among the following stakeholders in Slovenia: ND field researchers as well as some clinicians and diagnosticians, policy makers at the Ministry of Education, Science and Sport and the Ministry for Health, “Young Research Leaders” who are promoting the campaign against Dementia, Slovenian Members of the European Parliament, some civil society organisations dealing with this phenomenon (e.g. “Spominica”) and other interested public.

Slovenian researchers are actively performing in JPND projects and initiatives. So far they have participated only in the first call – harmonisation of biomarkers. Two Slovenian research groups were successful in this call which is an excellent result for a small country like Slovenia. Unfortunately due to cuts in the National State budget we have not been able to participate in more calls so far.

Concerning the initiatives in Slovenia for supporting researchers willing to apply for JPND funding, at the moment there exist only the strivings of the Directorate for Science at the Ministry of Education, Science and Sport for enabling the funds to be reserved in the 2016 National State budget for participation in the planned JPND calls for that year.

When asking ourselves what are the main benefits for Slovenia to participate in JPND we can confirm that the benefits are multi-fold. Our participation in JPND is stimulating the Ministry of Health to develop a National Plan for addressing Dementia or Neurodegenerative Diseases. As well, Slovenian researchers are re-focusing on this area and follow the funding calls. The JPND Strategic Research Agenda is a kind of “lighthouse” for Slovenian policy makers in diverse Ministries and Research Performing Organisations. In addition, an informal group of the “Young Leaders for Promotion the Dementia-related issues” is being created which is influenced by JPND efforts in this area. Last but not least, a project proposal for a “Teaming” call within the EU research and innovation programme Horizon 2020 has been successful in the 1st phase also due to the important component of the Dementia issues.

JPND efficiently addresses the problems which are already very serious in our country and will be even more dramatic in the future.
Therefore we have to prepare adequately and quickly for these new phases of challenges ahead. We are trying to stimulate Slovenian Ministry of Health and other Ministries to more actively organize themselves towards creating effective solutions for the increasing problems deriving from the Dementia challenge. Participation in the MB of JPND supplies us with comprehensive information and understanding of the complexity of the phenomenon. Since the size of the global challenge of the Alzheimer disease is so dramatically expanding we all have to engage now and fully! JPND is addressing this challenge bravely and efficiently. It is even providing some solutions already!

**PL2.3. Changing the perceptions and image of dementia**

**ORHEIM Alv**

A few years ago, my wife Berit very gently questioned my memory loss and apparent loss of concentration. I was baffled. Me, only 60 years old? My grandpa had dementia, but he was 93 when he died. I could not have these old-man symptoms. The eye-opener to me came when several members of the audience after a lecture in geology told me that I had repeated myself far too often. During that lecture I could not remember which topics had been covered, and for the sake of logical arguments, I thought it better to repeat myself once more, or once more or even more! Having had this fairly rough awakening, I realised my best option was to face dementia with open eyes, and accept it as a fact of life. And of course although no one is pleased when I tell them of my condition, everybody along my road has joined in and provided necessary support. In the general community, there is a need for basic knowledge transfer. The primary facilitators of this are people with dementia themselves and their carers.

In this presentation, I am going to talk about how my own perception of dementia has changed as a result of my personal experience. I will also share my experience of how people have reacted to me having dementia.

**PL2.4. The OECD approach to comparing and benchmarking dementia care**

**PEARSON Mark**

Most OECD countries have implemented policies to improve dementia care and many have published dementia strategies. There is a strong desire to be able to compare policies and their impact internationally, but this is not currently possible. There is little data on dementia and no internationally comparable indicators of the quality of care.

The OECD has begun working with our member countries and other partners to change this situation. Our approach is two-pronged: we will make the best comparisons that are possible now, and we will lay the foundations so that we can make better comparisons in the future, focusing on the quality of care and outcomes.

In the absence of internationally comparable data on dementia, we can make qualitative comparisons of policy approaches. Our starting point is a policy framework jointly developed by the OECD and WHO, and which has broad international support from OECD member countries and attendees at the First International Conference on Global Action Against Dementia (hosted by the WHO in March 2015). The framework identifies ten key objectives that all countries should consider and highlights possible policy approaches for each. By asking countries systematic questions about their policies and supporting evidence and evaluations, we can map out and compare what countries are doing now.

In the longer term, our ambition is to develop robust, internationally comparable indicators of the quality of dementia care and outcomes for people with dementia and their carers. The first step is to comprehensively review the current state of play in terms of what countries collect, what is possible with existing data systems and what changes would be needed to collect better information on dementia. This will provide us with the information we need to map out the path towards collecting internationally comparable indicators.

**PL3.1. Arts programmes for people with dementia: what are their effects?**

**WOODS Bob, WINDLE Gill, HOWSON Teri, ALGAR Kat**

There are numerous examples around the world of creative artists working with people with dementia and many anecdotal accounts of the impact this interaction can have. There are fewer systematic, rigorous evaluations of the effects, despite the growing literature on psychosocial interventions in general.

This presentation reviews the evidence-base for creative arts programmes in dementia care, and addresses some of the methodological issues that arise in evaluations of this type. The results from a series of studies led from Bangor University, attempting to develop a methodological framework that is both rigorous and capable of capturing some of the key elements of arts programmes in dementia care will be presented. These include the Dementia & Imagination study where mixed methods, including direct observation (Algar et al., 2014) as well as self-report quantitative outcome measures, are incorporated in the evaluation of a 12-week visual arts intervention. Programmes have been evaluated in both care homes and community settings, and observational methodologies developed and refined. More than 70 people with dementia have participated to date. Case studies of impact and engagement are presented, and consideration given as to ‘what’s special about the arts?’

It is argued that engagement in arts activities may, for the person with dementia, be different from engagement in other activities, but not necessarily greater in impact. However, there may be a particular effect on others witnessing the engagement – including staff, families, artists and the wider community. Any evaluation should seek to take multiple perspectives, recognizing that having a wider impact may bring a knock-on effect of reduced stigma for those living with dementia in the future.

‘Dementia & Imagination’ is funded by the UK Arts & Humanities Research Council (PI: Gill Windle)
PL3.2. People with dementia as partners: the example of the Scottish Dementia Working Group

HOUSTON Agnes

In 2002, the Scottish Dementia Working Group (SDWG) was set up and I was delighted to become its first female Chair from 2010-2013. The purpose of the SDWG is to campaign to improve services for people with dementia and their families and to ensure that our voices influence the public policy that impacts on our lives. Since 2002, members of the SDWG have raised awareness at national and international conferences, spoken on radio and television and lobbied government and senior government officials on our needs as people living with dementia.

As a group we also acknowledge how research can influence, not only our lives as those living with dementia now but also those who will develop dementia in the future. We developed a research subgroup to inform research processes and the national research agenda and published our Core Principles for Involving People with Dementia in Research.

We have worked with Alzheimer Scotland and the Scottish Government to inform Scotland’s 2 National Dementia Strategies and will begin work on the third this year. This is a significant investment at a Government level in terms of people with dementia being treated as partners in dementia policy. It would be rare that any high-level dementia policy meeting did not now include people with dementia, so we have come a long way.

In my presentation, I will explain in more detail what the SDWG has achieved and how; but also talk about some of the challenges that go along with being a long-standing campaigning group and where we go next.

PL3.3. The dementia friends campaign in the UK: a vital element for the development of a dementia-friendly society

HUGHES Jeremy

Dementia is a challenge to society as a whole. Lack of awareness and understanding of dementia in the communities has a major impact of the quality of life of those living with dementia and their carers. Alzheimer’s Society has been leading the way to tackle the unacceptable stigma that surrounds dementia and working with organisations and communities to increase their dementia friendliness. From an initial commitment in 2012 to raise awareness of dementia and for 20 cities, towns and villages to be signed up to become more dementia friendly, we now have over 1 million Dementia Friends and over 90 communities committed and working to become dementia friendly in England. The UK has also been leading the way to promote and develop dementia friendliness at a European and wider global level. Dementia friendly initiatives across the United Kingdom are now positively changing attitudes and action towards dementia. Alzheimer’s Society’s Dementia Friends programme is our biggest ever initiative to change people’s perceptions of dementia. It aims to transform the way the nation thinks, acts and talks about the condition.

Dementia Friends was launched to tackle the stigma and lack of understanding that means many people with the condition experience loneliness and social exclusion. We need to create more communities and businesses that are dementia-friendly so that people affected by dementia feel understood and included.

Over one million people in the UK have become Dementia Friends in the first two years of the initiative. This number is made up of those who became Dementia Friends face-to-face, online and through their work at organisations such as Lloyds Banking Group and Marks & Spencer. As part of Alzheimer’s Society’s long-term commitment to help more communities and businesses become dementia-friendly, a new target of creating four million Dementia Friends by 2020 has been set. Alzheimer’s Society secured the backing of the Government for Dementia Friends and ran a national TV advertising campaign featuring celebrities alongside a person living with dementia.

National and local businesses and organisations, community groups, faith groups, individuals, young and old, who have become Dementia Friends now are committing themselves to go further and play their part towards creating a truly dementia friendly society through our Dementia Friendly Communities programme.

Dementia Friends, however, is only the first step towards creating a dementia friendly society. Dementia Friends is the start, not the end. By raising awareness and attitudes towards dementia we open the door to transforming the way every part of society – from the classroom to the boardroom – thinks and acts about dementia.

Countries across Europe are looking at ways to increase awareness and poor understanding of dementia. Hearing about the experience and success of Dementia Friends in England will provide delegates with a first-hand insight about the challenges and ways to successfully mobilise society to change the way they think and act about dementia.

PL3.4. Age and dementia as a risk factor for domestic violence: what can we do?

KOPČAVAR GUČEK Nena

Violence is abuse of power, and every violation of fundamental human rights. Violence as a destructive form of interpersonal relations is undoubtedly at least as old as the concept of the family. Each of the types of violence (physical, sexual, psychological, including neglect and economic violence) may occur in family relationships. Domestic violence includes intimate partner violence, violence against children (child abuse) and violence against older (elder abuse). Violence and neglect cause in the elderly unnecessary suffering, injury, pain, loss or violation of rights and it reduces the quality of life. Medical abuse, neglect, abandonment and economic violence are most frequent forms of violence in the people with cognitive impairment, such as dementia. The prevalence of various forms of abuse in the elderly in the developed countries is 4 to 6% in domestic settings, dementia being an important risk factor. Among older people living at home in European Union (EU) (about 142.9 million people) in the last 12 months prior to the survey 2.7% (approximately 4 million) older experienced physical violence, 0.7%
were sexually abused (about one million), 19.4% were exposed to psychological violence (approximately 29 million) and 3.8% to economic violence of (about 6 million). Violence is stated as the cause of 30% of all deaths in the elderly per year in EU.

Examples of good practices of raising awareness, improving education of lay and professional audiences and implementing new strategies will be presented and discussed. Healthcare, social care, non-governmental organizations and interested public have the potential to create a network for prevention, treatment and support for the vulnerable individuals, victims of family violence and people with dementia. Institut Antona Trstenjaka bridgeing intergenerational issues, Mreža Matja providing home care and assistance by volunteers and professionals and Emeritus University in Ljubljana are examples supporting the elderly and their families in Slovenia.

**PL4.1. Meeting the needs of people with intellectual disability and dementia**

McCARRON Mary, McCALLION Philip, REILLY Evelyn, BURKE Eilish, DUNNE Pamela, RACHAEL Carroll, WANG Boon Wan

A serious challenge today in Ireland and elsewhere is the growing number of people with intellectual disabilities (ID) and dementia. Reliance on past care practices is inadequate and general population responses are not sufficient. New data driven and evidence-based models are needed.

**Method:** Data was gathered from three sources – (1) 77 women with Down syndrome aged 35 years and older followed longitudinally with incident diagnoses of dementia established using the modified ICD 10 Criteria. (2) strategic planning data at one comprehensive services provider addressing changing demographics, ageing of persons with Down syndrome, challenges to current service models, residential and day programs, and skill issues for staff. (3) The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA), a large-scale, nationally representative study of people aged 40 years and over with an ID.

**Findings:** Among the critical findings were: (1) In longitudinal follow-up of 77 women with Down syndrome, over 80% are now presenting with symptoms of dementia, average age of dementia diagnosis was 55.4 years (SD = 7.14) and median survival, 7 years after diagnosis. (2) Total engagement of staff, families and people with ID, consideration of five and 10 year potential for dementia, willingness to modify every service environment and commitment to training for all staff are critical components to a successful system wide dementia strategy and (3) Prevalence of dementia in persons with Down syndrome doubled from 15.9% to 29.5% over the 3 year period from IDS-TILDA Wave 1 to Wave 11. Tracking incidence of dementia and the impact of responses are possible using longitudinal datasets such as IDS-TILDA.

**Conclusion:** The confirmed high risk levels for dementia among people with Down syndrome and for people with other types of ID seriously challenge services and services providers but data is emerging on responsive strategies demonstrated to work.

**PL4.2. Dementia, ethics and technology**

TOPO Pavi

As part of our everyday activities, technology influences our way of thinking and understanding the world. Thus, it is worthwhile to examine how technology shapes our idea of what it means to live with dementia and how readily the benefits of technological development are accessible to people with dementia, their close ones and professional carers. This presentation has three aims: 1. to summarise the technological solutions available to people with dementia, their close ones and carers, 2. to review the methodological approach used in the research designed to evaluate the value of such solutions, 3. to discuss how some crucial ethical issues concerning technology and dementia could be tackled. The presentation is based on a literature review, interviews with spouses of people with advanced dementia and analyses of newspaper texts on dementia and technology.

**PL4.3. Managing and preventing behavioural and psychological symptoms in dementia**

ZALAR Bojan, ŠTRUKELJ Katarina Barbara

Numerous and diverse symptoms occurring as consequence of changes in cognitive functions and memory loss can be described by the descriptive term dementia; the dementia phenomena make normal life impossible. Though tending to be terminologically equivalent and correlating with functional decline, there are, however, also other symptoms not caused by the decline of cognitive processes, which accompany dementia. Cognitive dysfunctions are increasing progressive, behavioural and psychological symptoms in dementia (BPSD) tend to fluctuate, psychomotor agitation occurring frequently. Behavioural and psychological phenomena symptoms in dementia are demonstrated in delusions and hallucinations, irritability, disinhibition, agitation, anxiety, apathy, depression, aberrant motor behaviour. Sleeping and appetite disorders are also present. It is usually the BPSD phenomena which lead to the diagnosis of dementia. Study of dementia is extremely comprehensive and including neuropathological, neurochemical, genetic, phenotypical, molecular-biological, psychological, sociological, and social factors. Prevention and treatment of behavioural and psychological symptoms in dementia requires new insights and approaches in the entire scope of dementia.

**PL4.4. The last taboo: Dementia, sexuality and intimacy**

HOOGVEEN Frans

Intimacy and sexuality are basic human needs that are intrinsic to people’s sense of self and wellbeing. Regardless of age, individuals require companionship, intimacy and love and yet for older people this intrinsic right is often denied, ignored or stigmatised. For older people with dementia the problem is even worse: they face the ‘double jeopardy’ of being old and cognitively impaired. Experiencing intimacy is vital for the quality of life of people with dementia. This may include sexual behaviour as well. Professional caregivers should be aware of this and help to allow the fulfillment of this basic human need. A number of good practices will be presented and discussed.
Lilly and Alzheimer’s Disease

For more than 25 years, Lilly has been committed to Alzheimer’s disease (AD) research and development, during which we’ve made significant scientific advances. We recognize the significant burden AD causes for patients, caregivers, and our society and remain committed to making life better for those affected by AD around the world.
SS1. Living well with dementia

SNELL Rozel, CRONQVIST Raoul, HOUSTON Agnes, BALÁČKOVÁ Nina

In this symposium, which is organised and run by the members of the European Working Group of People with Dementia (EWGPWD), Rozel, Raoul, Agnes and Nina will share their experience of living well with dementia, assisted by Brian, Milja and Donna. The underlying themes include post-diagnostic support, self-management in dementia, what “dementia friendly” means and close friends and family.

Rozel will be talking about her journey from when she was first diagnosed with Alzheimer’s. She will talk about things that have happened to her from her own point of view, about some of the times when things did not go as she would have liked and about what having her husband as a carer 24/7 means to her.

Raoul will share his experience of living with dementia in the form of his own case study. He will explain what kind of post-diagnostic support he has received and the impact this has had on his life.

Agnes will tell you about her exciting work on dementia and sensory challenges. Dementia is more than memory. The sensory challenges are huge and need to be addressed. Come along and hear what Agnes did to cope with these issues.

Finally, Nina will describe the impact that dementia has had on her life. She will explain how the diagnosis of dementia has resulted in a new way of life, that it is necessary to be active and that when you have the support of family and friends, everything is easier. She will emphasise that it is not always easy but that she is still happy.

So come along to what promises to be an informal but lively and moving session involving all the members of the EWGPWD. As each of the four presentations will last about ten minutes, there will be plenty of time for questions and for the exchange of experiences.

SS2. EPAD, an innovative private-public partnership for the prevention of Alzheimer’s dementia

BADGER Shirlene, LOVESTONE Simon, VAN DER GEYten Serge

There is an urgent need for new treatments for Alzheimer’s disease. The number of people affected worldwide is expected to reach over 100 million by 2050, yet despite intensive efforts over many years, there is still no cure for Alzheimer’s and little in the way of treatments. Memantine, the last drug for Alzheimer’s disease was approved over 10 years ago.

Today, research increasingly focuses on ways to prevent the onset of Alzheimer’s disease or the progression to Alzheimer’s dementia in the first place. The EPAD project is pioneering a novel, more flexible approach to clinical trials of drugs designed to prevent Alzheimer’s dementia. Using an “adaptive” trial design should deliver better results faster and at lower cost.

This innovative trial design has already proven effective for testing new treatments for breast cancer. The EPAD project is pioneering this approach in Alzheimer’s disease. By adopting this approach, the project expects to be able to identify ineffective medicines earlier in drug development and so avoid failures in more advanced (Phase III) trials. By setting up a cohort of patients ready to enter trials and creating a pan-European network of trial sites, EPAD will also make clinical trials more efficient.

This interactive symposium will give you an opportunity to learn more about this exciting project and ask questions to some of the lead researchers involved in EPAD:

According to Simon Lovestone, Professor of translational Neuroscience at the University of Oxford “the long pre-clinical evolution of Alzheimer’s disease presents an opportunity and a challenge; the opportunity being to treat the condition before it becomes clinically apparent the challenge being the enormous one of performing practicable clinical trials in this early phase.”

Serge Van der Geyten, the EPAD Coordinator and Director, Neuroscience External Affairs at Janssen Research and Development will highlight the commitment and expectations of the pharmaceutical industry who sees the project as an opportunity to avoid the mistakes from the past, learn from each other and de-risk our compounds in a much faster and clearer way, hopefully bringing better, more effective drugs to patients faster.

Shirlene Badger, the lead of the EPAD work package on ethical, legal and social implications and senior researcher at the University of Cambridge, will show how social issues and the inclusion of participant voices are central to the project. She will discuss key ethical questions with the audience.

This symposium is organised by EPAD, a project which has received support from the Innovative Medicines Initiative Joint Undertaking under grant agreement n° 115736, resources of which are composed of financial contribution from the European Union’s Seventh Framework Programme (FP7/2007-2013) and EFPIA companies’ in kind contribution.

SS3. Social participation and dementia: a descriptive qualitative study from the perspective of persons with cognitive problems and their caregivers

DONKERS Hanneke, GRAFF Maud, VAN DER VEEN Dinja, NJHUIS-VAN DER SANDEN Ria, VERNOOIJ-DASSEN Myrra

Introduction: Social participation is of great importance as part of successful and healthy aging, since it is associated with physical and mental health and well-being. The aim of the current study was to explore how community-dwelling older people with cognitive problems and their caregivers (dyads) perceive social participation and which factors are perceived as influencing.

Methods: In this qualitative study we performed thirteen semi-structured, in-depth interviews with dyads. The interviews were thematically analysed through a content analysis.

Results: All dyads indicated a decrease in social participation. This reduction applied to all people with cognitive problems and
for most caregivers who were married, and to a lesser extent for the non-spouse caregivers. The majority of both the people with cognitive problems and their caregivers was satisfied with their own level of social participation. However, most caregivers tended to be dissatisfied with the social participation level of the persons they cared for. The analysis of the interviews resulted in five themes of influencing factors for social participation: (1) behavioural factors; (2) physical factors; (3) social environmental factors; (4) physical environmental factors; (5) activity related factors.

Discussion: While most non-spouse caregivers tried to improve the level of social participation, spouse caregivers and people with cognitive problems generally lowered their expectations and expressed feelings of acceptance or satisfaction with their own level of social participation. The discrepancy between satisfaction with social participation among caregivers and the people they care for, results in tension regarding respecting individuals’ autonomy and the prevention of negative heath consequences associated with reduced social participation.

SS3.4. Decisions in the lives of people with dementia: differences between those living alone and those living with their informal caregiver

CROEN – VAN DE VEN Leontine

Objectives: The erratic course of dementia makes the dementia trajectory unpredictable and leads to uncertainty. The changing situation of people with dementia requires many decisions over time. However, empirical evidence about what decisions are made when is lacking. This evidence is necessary for a proactive support of people with dementia. We aim to provide insight into dementia trajectories by studying what decisions are made, and when, from the perspectives of the care networks of people with dementia.

Methods: In this longitudinal multi-perspective study, we interviewed 113 respondents three times in 12 months (285 interviews). The respondents belonged to 23 care networks including people with dementia, their informal caregivers and professionals. Our analysis was multi-layered: 1) We determined the decisions made in our care networks using content analysis. 2) We built timelines placing the decisions of each care network in chronological order. 3) We used constant comparison to determine patterns in the content and sequence of decisions made.

Results: Our analysis show four themes of decisions in care networks of people with dementia: 1) managing daily life, 2) arranging health care and support, 3) living in society, and 4) preparing for the future. We found differences in the content and sequence of decisions between people with dementia living alone and those living with their informal caregiver. From this observation we developed two distinctive decision trajectories including marks to which certain types of decisions could be related. Examples of marks in those living alone are safety concerns, safety incidents and hospitalization. Examples of marks related to people with dementia living together are inactivity of the person with dementia and overburden of the informal caregiver.

Conclusion: The differences in content and sequence of decisions made in care networks of people with dementia living alone and those living with their caregiver require a different approach in preparing for decisions that lie ahead.

SS3.5. How accessible are grocery shops for people with dementia? A qualitative study

BRORSSON Anna, ÖHMAN Annika, LUNDBERG Stefan, CUTCHIN Malcolm P., NYGÅRD Louise

People with dementia who live in ordinary housing need to perform activities outside home such as visiting friends, talking walks and doing grocery shopping. This study identifies and examines characteristics that may influence accessibility in the space of a grocery shop as perceived by people with dementia. A grounded theory approach was used in the data collection and analysis (photo documentation and focus groups interviews with informants with dementia). The categories “illogical arrangement”, “overload of products”, “information and people”, “visual illusions” and “intrusive auditory stimuli” showed characteristics in the grocery shop that influenced on how accessible and usable the informants experienced a shop to be. Further, personal capacities, i.e. capacity to find, stay focused and concentrated, meet stress, remember, interpret and discriminate sensory impressions through hearing and sight, also came to the fore as important. Such characteristics of both the shop and the person need to be taken into account when supporting people with dementia in maintaining participation in social activities such as grocery shopping.

This study is one of 4 sub-studies in Anna Brorsson’s PhD-thesis; Access to everyday activities in public space: Views of people with dementia. Karolinska Institutet, Stockholm, Sweden, 2013. (This sub-study is submitted but not yet published):

It is also part of an ongoing international project “Access to and usability of places and activities in public space”, led by Louise Nygård, Professor, Karolinska Institutet.

SS3.6. Narrative care: discussing the impact and benefits of an individual life review intervention for older persons with and without dementia

SPRUYTTE Nele, MESTDAGH Annelien, LAURENT Josefien, DUBOIS Cindy, VAN AUDENHOVE Chantal

Introduction: Many older persons suffer from depressive feelings. It is important to recognize sub-threshold depression and to prevent the development of major depression, however, preventive strategies do not specifically focus on frail older adults. In Brussels (Belgium), a community mental health care team developed an individual life review intervention where life story writers visit frail older persons at home. In about 12 thematic sessions the older person is encouraged to tell his/her life story. The life story writer facilitates the life review process and at the end a life story book and individual ‘identity circle’ is handed to the participant.
Aims: This presentation will first present the results of the effectiveness study we conducted on ‘Narrative Care’. It was hypothesized that Narrative Care diminishes the feelings of depression, anxiety and loneliness and enhances the feelings of mastery, self-esteem and resilience. Second, we will discuss the possibilities of ‘Narrative care’ for older persons with dementia.

Methods: In a pretest-posttest design we investigated the impact on depressive feelings, loneliness, anxiety, mastery, self-esteem and resilience in participants of Narrative Care. These concepts are measured with self-report questionnaires, administered by the life story writers at home with the participants. Qualitative interviews were performed with participants, including two children of persons with dementia who had entered the nursing home after the intervention.

Results: The intervention has a large number of drop-out of participants, mainly because of their frailty and old age. Non-response-analysis shows no differences between the initial group and the group that completed the whole interventions and both measurements. Significant effects on the self-esteem and anxiety scale were found in the 44 persons that completed both measurements. Participants feel less anxiety and more self-esteem after completion of the sessions than before. No significant effects were found for depression, loneliness, mastery and resilience. Both nursing home staff and the children of the persons with dementia found the life story book and identity circle of Narrative Care a valuable method for smoothening the transition from home to the nursing home.

Conclusions: Anxiety reduction is known as an effect of participation in a life review intervention. Contrary to the expectations no effect was found on depressive feelings. This study has methodological limitations (e.g. no control group, no blind measurements), however, it is promising that through attention for the individual life story it is possible to strengthen the identity and feelings of self-esteem of frail older persons. Future studies with more rigorous design and methods and with specific attention to persons with dementia are warranted.
Parallel Sessions

P1.1.  Research into practice: People with dementia creating change in the Joseph Rowntree Housing Trust (JRHT)

BLAKER Katherine, FLORY Eddy

The Joseph Rowntree Foundation (JRF) has funded a three year research programme seeking out solutions to enable people to live well with dementia.

Joseph Rowntree Foundation (JRF) has funded a three year research programme seeking out solutions to enable people to live well with dementia.

One strand of this research has explored how taking a community development approach to building a dementia-friendly organization can deliver change for residents, staff and their families, and the wider communities around JRHT workplaces.

In this action research programme staff have worked with people with dementia to deliver four projects of benefit to the wider community, namely, 1) a dementia friendly courtyard garden in a residential care home, 2) refurbishment of a community centre, 3) development of a dementia-friendly public park, 4) distribution of small grants to community groups to benefit people with dementia.

In this presentation, Katherine, who as Community Development Manager, has been coordinating this programme of work will:
  
a) explain the rationale behind the community development approach adopted by JRHT;
  
b) share how opportunities to involve people with dementia were selected;
  
c) describe via a short film, how people with dementia informed the refurbishment of the community centre where they meet regularly
  
d) share her personal learning and offer suggestions on issues to consider when planning to involve people with dementia in your own work.

The Joseph Rowntree Foundation is an endowed foundation based in the north of England that invests in social research and aims to influence policy and practice via demonstration. The Joseph Rowntree Housing Trust is a housing and care service provider delivering general needs social housing, housing with care and residential care. Both organisations are based in York, UK.

P1.2.  Reflections from the Irish dementia working group and Alzheimer Society of Ireland on the benefits and challenges of participating in dementia research

ROCHFORD-BRENNAN Helen, BEGLEY Emer, RYAN Kathy

The publication of Ireland’s first National Dementia Strategy in December 2014 included a commitment to dementia research underpinned by dedicated funds of €4.7 million, the largest ever State investment of its kind. Running alongside this investment is an increased national focus on public patient participation in research. These two pull factors are creating an increased national demand for the involvement of people with dementia in research.

Around this same time members of the Irish Dementia Working Group, having a keen interest in the area of research, formed a research subgroup. Members of this group want to engage in research, taking a partnership approach, engaging beyond passive research participation and to develop more innovative and leadership roles within the dementia research community.

This presentation will reflect on these pull and push factors for the increased engagement of people with dementia in research, both from an organisational and individual perspective. The activities of the research subgroup, such as involvement in the ASI’s research review committee, membership of an international global research project advisory group and engaging in more traditional research roles will be discussed. The presenters will reflect on the challenges faced, identifying innovative approaches to overcoming these while identifying the benefits of research engagement to both the organisation and to individual working group members.

P1.3.  Developing the involvement of people living with dementia and carers in policy making

DALRYMPLE Amy

Background: Alzheimer Scotland is committed to making the voices of people living with dementia, and carers, heard and acted on by policy makers and decision makers. We have successfully supported the Scottish Dementia Working Group and the National Dementia Carers Action Network to campaign at national level, influencing the content and implementation of Scotland’s National Dementia Strategy.

New legislation means that health and social care agencies have a duty to involve people who use services and carers. We therefore identified a need to work harder to ensure that as wide a range as possible of people with dementia and carers have the opportunity to influence policy and strategy development – ensuring greater impact at local and regional level, and including people who are not able to be active in the national campaigning and working groups.

Aim: This programme of work seeks to:

- Increase the involvement of people with dementia and carers in policy making in Scotland through involvement in Alzheimer Scotland’s policy development work, and through supporting direct links with statutory sector decision makers.
- Identify what we can do to involve people with dementia and carers in policy making, and establish which are most appropriate in any given situation.

Methods and key findings: Beginning with an appreciative inquiry approach, this programme has engaged colleagues from across Alzheimer Scotland, recognising that a broad range of expertise and buy-in is required to successfully achieve the programme aims. A wide ranging consultation within and beyond the organization identified:

- Good practice
P1.4. Partners in projects: Preparing people living with dementia and carers in policy making, and outline key remaining good practice, demonstrate what works in the involvement of people with early-stage dementia who wish to become involved in policy making, and outline key remaining barriers, with suggestions about how they can be overcome.

Conclusions: In a European context, Scotland is a good testing ground for best practice, as this principle enjoys wide acceptance among statutory sector decision makers as well as among campaigning organisations like Alzheimer Scotland. This presentation will provide an overview of the development of good practice, demonstrate what works in the involvement of people with dementia and carers in policy making, and outline key remaining barriers, with suggestions about how they can be overcome.

P1.5. I survive best by being active

KIMENAI Jasper, DANEN Saskia

For a person with dementia and her caregivers it is important to be part of the community, both to be able to make a contribution and to participate in the society. To make this participation possible Alzheimer Netherlands is focusing on two strategies with their program Dementia Friendly Society.

Strategy 1: the emphasis is on spreading knowledge and increasing awareness within civil society about dementia and its impact on a person’s life. The training given by Alzheimer Netherlands and its 51 local branches to local governments, social- cultural organizations, schools, supermarkets, police and firemen, banks and museums.

Strategy 2: the emphasis is on being able to participate in the society in many ways. A good example in which Alzheimer Netherlands participates is ‘Young and Old (learn) together’. This project takes the viewpoint that people with dementia have many talents and that those talents can also be utilized in education. People with dementia may volunteer to work in education or to be an expert. Students can learn a lot from their experience as a ‘patient’ and the people with dementia feel they continue to make a meaningful contribution.

P2.1. Has Ireland’s first National Dementia Strategy made dementia a national priority?

LEONARD Tina, MARTIN Gerry

Ireland’s first national dementia strategy was finally published by the Department of Health in December 2014. The promise of its publication, as outlined in the 2011 Programme for Government, came years after The Alzheimer Society of Ireland first called for dementia to be made a national health priority. The intervening years of lobbying political parties, local and national politicians resulted in a government commitment to address dementia at a national, strategic level.

This presentation will outline the principles underpinning the strategy, the six priority areas and the actions for implementation. It will reflect on the achievements within the strategy, how it has the potential to bring systematic and real change for people with dementia and their family carers living in Ireland.

However, like all policy documents developed in a collaborative...
manner and compounded by a lack of funds for the strategy’s implementation, there are certain aspects of the strategy that have not met expectation. This presentation will reflect on where the Alzheimer Society of Ireland feels additional action is needed to ensure that dementia is made a national priority – not only examining the contents of the strategy, but plans for its implementation and monitoring as well as the leadership that has been shown at a national level.

P2.2. Involving people with dementia in new dementia strategy

ENGEDAL Knut, TOFT Anne Kjersti

Background: Norway was one of the first countries globally that launched a national dementia strategy operating from 2007 to 2015. The strategy focused on day-time activities, better adapted living arrangements and increased knowledge. The strategy has had an impact for local communities and for dementia care. However, Norway still faces challenges, and some of the goals have not been achieved.

Method: The Norwegian Health Association has been working over several years to get the government to commit to the making of a new strategy. The Norwegian Ministry of Health and Care Services were also encouraged to include people with dementia and their carers in developing the strategy, inspired by the work in England and Scotland. In the fall of 2014 the Ministry initiated a working group and invited the Norwegian Health Association and Norwegian National Advisory Unit on Ageing and Health. The working group planned and arranged seven dialogue meetings all over Norway. Every meeting had an introduction from the Ministry and a presentation by a person with dementia. Then all participants performed in structured group conversations.

Results: The dialogue meetings gathered over 700 persons with dementia, carers, volunteers and employees in the local health and care services. The main topics that came up in the dialogue meetings were more involvement of people with dementia, timely diagnosis, case management, more knowledge in health services and society, the need for meaningful activities and better quality in nursing homes.

Conclusions: This is a historic involvement of people with dementia in Norway. The Government benefited from this process as they learned more about the challenges still existing in Norway and which actions should be taken, from those who live and work with dementia every day.

P2.3. The global “young leaders address dementia” initiative to support the World Dementia Council

BREZOVAR Simon, ZIBERNA Lovro, LEIST Anja K.

The work of the World Dementia Council and the Global Action Against Dementia program in the G7 countries advances coordinated action against dementia. Within this framework, the UK Science and Innovation Network organized a series of young leaders events in Canada, Japan, the US and Europe in 2014 and 2015, in association with the thematic Global Action Against Dementia Legacy Events. The European Young Leaders Event was also open to researchers and professionals of non-G7 countries participating in the EU Joint Programme – Neurodegenerative Disease Research (JPN). The workshop-like events sought to develop creative and innovative ideas to address the challenges presented by dementia. The resulting declaration together with four top recommendations in research, care, cure, and awareness were fed to the WHO Ministerial Conference on Global Action Against Dementia in Geneva in March 2015. The Young Leaders, representing different sectors of experience and expertise, have built a network and are continuing their (virtual) collaboration to address the challenges presented by dementia. On behalf of the European Young Leaders’ Network, one of the delegates participating in both the European event and the WHO Ministerial Conference will share the developed recommendations, ranging from inter-lab agreements to share funding, data, and research material (research) to standardized post-diagnosis support (care), funding of high-risk high-reward projects (cure), and education at school, of clinicians and care professionals (awareness). Ongoing developments of the initiative are reported.

P2.4. Moving forward: what should be the focus of dementia strategies in 21st century?

GOLDSHART Oliver, JACOBSEN Wienke, SLEVIN Patrick

The World Health Organisation (WHO) has declared dementia a public health priority. In this context, a question now remains: what should be the focus of national and global strategies considering dementia is a public health issue? WHO describes public health as organized measures (whether public or private) to prevent disease, promote health, and prolong life among the population as a whole – we believe this definition should act as a blueprint for future dementia strategies. By looking at current research in Germany and Ireland, this paper will create a rationale for why early diagnosis, community strategies, and independent living, should be the focus of 21st century efforts to provide and deliver more effective and holistic care at the public level as well as the individual level.

Early Diagnosis: Clinical anti-amyloid drug trials with PWDs have not yet provided satisfactory results. But the fact that biomarker changes can be detected decades before onset has raised the hope that anti-amyloid therapy is applicable and more effective in earlier stages. In causal therapy however, limitations exist with early diagnosis, lack of an accurate prognosis, and a strong evidence base, which in turn leads to contradictory information in the media.

Community Strategies: Recently, Germany adopted a national Alliance for people with dementia but regional framework conditions must also be considered. Schleswig-Holstein is the first state, to develop a dementia plan on behalf of the state government. The promotion program of the German Federal Ministry for Families “Local Alliances for people living with dementia” focuses on improving inclusion and quality of life and supports communities in the implementation of local projects on the topic of dementia.
Independent Living: Connected Health technologies facilitate the remote delivery of healthcare, shifting the emphasis of chronic disease care to self-management and thus, independent living for patients in their own home. This is an emerging area with the potential to transform dementia healthcare and service delivery by reducing burdens on caregivers, health systems, costs, and improving the quality of life for our ageing populations.

P2.5. Greek national observatory for dementia and Alzheimer’s disease: ensuring the implementation of national dementia strategy

SAKKA Paraskevi

According to the latest figures, there are 200,000 people living with dementia in Greece and 400,000 caregivers looking after them. These numbers will increase dramatically in the years to come, making dementia one of the most crucial medical, societal and economic challenges in Greece, as is all over the world.

Recognising the magnitude of the issue and responding to lobbying efforts from the Alzheimer Associations, in October 2013, the Greek state assigned a working group to develop a National Dementia Strategy. In September 2014, after a consultation period, the group presented the final draft. Key priorities of the strategy are to raise public and professional awareness, promote early diagnosis and intervention and create support services towards ameliorating the quality of life of people with dementia and their caregivers.

In December 2014, the Greek Parliament enacted a law, supported by the entire Greek political spectrum, to ensure the implementation of the strategy. This law authorises the establishment of an independent public institution: the National Observatory for Dementia and Alzheimer’s disease. The Observatory will act under the guiding principles of respect, support and promotion of patients’ rights and will fulfil the following objectives:

- Ensure the implementation and subsequent updates of the National Dementia Strategy.
- Provide official guidance to the Parliament, the Ministry of Health and other public authorities on legislative and policy measures related to dementia.
- Coordinate and promote the work of public and nongovernmental agents and associations, in order to ensure efficient services to patients and their caregivers.
- Provide specific guidance for organising and promoting the national policy in research and education.
- The Observatory has an interdisciplinary profile engaging health professionals, scientists, caregivers and other members with specific expertise and its operation must not be affected by governmental changes.

P3.1. Understanding the causes and solutions for crises in dementia

ORRELL Martin, TOOT Sandeep, LEDGERD Ritchard

Many people with dementia and their carers experiences crises with the common consequence of a breakdown in care and the potential for hospital admission. The consequences of this can be that the person with dementia is no longer able to be supported in their own place which can result in a permanent loss of their home and long term admission to a nursing home. This usually means quality of life is lower and costs are higher, even though with the right support they could potentially be maintained at home for considerably longer.

Little is known about the precise causes of crisis and even less about the best measures to manage them. A series of studies are presented which look at the risk factors for and the precipitants of crisis from the point of view of family carers, staff, and the people with dementia themselves, and related work identifies the best methods for the prevention of crises and the most useful ways to intervene and prevent admissions. Methods include systematic reviews, focus group studies, a national survey and consensus methods. The results showed that falls, infection and delirium were highly rated as risks factors for crises. Carers and people with dementia rated aggression as less important but severity of memory impairment as much more important than staff did. Education and support for family carers and home care staff was highly valued. Well trained home care staff, communication equipment, emergency contacts and access to respite were highly valued for managing crises. In conclusion, understanding potential crisis situations and interventions to support people with dementia and their carers is critical to providing effective support.

P3.2. Online training of carers of people with dementia; evaluation results of the European STAR training portal

MEILAND Franka, HÄTTINK Bart, VAN DER ROEST Henriëtte, KEVERN Peter, ABIUSO Francesca, BENGTSSON Johan, GIULIANO Angelo, DUCA Annalise, SANDERS Jennifer, BASNET Fern, NUGENT Chris, KINGSTON Paul, DROES Rose-Marie

Background: A shortage is expected of professionals available to care for the growing number of people with dementia. As a result, untrained informal carers and volunteers will increasingly provide care. To promote effective care in dementia and avoid carer overburdening, carers need to become properly skilled. To address this need, a multilingual e-learning portal has been developed and evaluated within the European STAR project. The final results of the evaluation of the STAR training portal will be presented.

Methods: A randomised controlled trial was performed among 142 informal carers, volunteers and professional carers in the Netherlands and the UK. Online standardised questionnaires were used at baseline and after two-four months.

Intervention: The training portal consisted of eight modules, two of which were deemed to be of a basic level and six additional modules at intermediate and advanced levels. The experimental group had
P3.4. Spreading the word: multiplication of best practice in carer support through a new apprentice scheme in reminiscence arts in dementia care and evaluation of this scheme

SCHWEITZER Pam, JANĚCKOVÁ Hana

Summary: Last year, the European Reminiscence Network developed a training and apprenticeship scheme to spread the word concerning the effectiveness of reminiscence in dementia care in supporting the central relationship between family carer and cared-for. This new apprenticeship scheme, which aims to train more workers in a fully tested and very positive intervention, is being piloted across ten EU countries all following the same pattern and leading to a certification in group facilitation of the “Remembering Yesterday, Caring Today” project.

Apprentices in each country attend an initial 2-day training course, then participate in at least 6 of 10 weekly practical sessions with families affected by dementia. They gain experience in running some of the activities themselves and then work in small teams to deliver entire sessions themselves. They receive feedback from experienced group leaders and from one another. The written work component of the apprenticeship measures their level of reflective practice and new learning against an agreed marking scheme. The first 20 apprentices have completed their course in the UK, almost all of them freelancers with a community arts background who intend to develop the work with new families in different parts of the country. Across the partner countries 100 apprentices have been accredited.

We are now extending the scheme, with at least two more groups of apprentices, to ensure there are more people able to deliver this highly effective intervention in the future.

In this paper, we shall quote from the recorded experience of the apprentices and reflect on the idea of accrediting an internationally shared intervention, showing how modifications to the programme have enabled it to succeed in different countries, and how project partners with different backgrounds (e.g. Alzheimer Societies, day centres, care support projects, community arts projects) have interpreted the brief while staying true to the spirit of the project. We shall also share information concerning evaluation of this project.
P3.5. **Natural4DEM: results of a qualitative pilot study into personalized nature based interventions for people with dementia**

**CERRITSEN Debby, VAN VLIET Deliane, HENDRIKS Iris, DRÖES Rose-Marie**

**Background:** For people with dementia, nature and outdoor spaces can provide a stimulating environment with exposure to light and sensory experiences as well as engagement in pleasant activities. Being in nature is often either not available for nursing home residents with dementia or underused despite easy access to it. Outdoor spaces (gardens, parks) often are available - also for home dwelling persons with dementia, but their use must be further improved.

**Aim:** 1) investigate the views of persons with dementia on the importance of nature and outdoor spaces for their quality of life (QoL); 2) create a checklist of what people experience as important for their QoL in nature and outdoor spaces; 3) develop several nature/outdoor space wellbeing-interventions for people with dementia, especially for persons with behaviour and mood problems; 4) pilot-test these interventions, investigating possible effects and feasibility.

**Method:** Focus-group interviews and semi-structured interviews with persons with dementia were conducted. The interventions were pilot-tested and evaluated by 15 persons with dementia. Feasibility was also studied, by interviewing professionals in dementia care.

**Results:** We identified various aspects of nature and outdoor spaces that people with dementia consider important for their well-being/QoL, e.g. health (fresh air, exercise) and rest (relaxing, silence, getting calm). Based on these, a checklist linking QoL-domains to nature/outdoor activities was developed to inventory what activities a person with dementia could undertake. Subsequently, a decision tree tool for person-centered nature interventions was created. The tool was presented to professionals caregivers and persons with dementia and adapted according to their feedback.

Momentarily, a pilot-study is conducted into the person-centered nature interventions for people with behaviour and mood problems (n=15) in day-care centers and nursing homes in three regions of the Netherlands.

**Conclusion:** The pilot-study ends May 2015. Results on effects and feasibility of the interventions are presented at the conference.

P4.1. **National audit of memory clinics in England: a comparison of findings**

**HODGE Sophie, HAILEY Emma**

In 2013 the Royal College of Psychiatrists were commissioned to conduct an audit of memory services in England. The aim of the audit was to collect and report information from all memory clinics in England, including waiting times, patient numbers, costs, aspects of service provision, involvement in research and membership of the Memory Services National Accreditation Programme (MSNAP). This audit was repeated in 2014 and results from the 2 years were compared.

The key differences were:
- Clinics in 2014 saw on average 30.9% more patients than in 2013 and conducted 6.0% more assessments
- The average waiting time for an initial assessment increased from 5.2 weeks to 5.4 weeks
- The longest waiting time for an initial assessment was 32 weeks in 2014, compared with 25 weeks in 2013
- There was a 19% increase in the number of people with dementia attending Cognitive Stimulation Therapy (CST)
- There was an 8% increase in the number of carers accessing post-diagnostic education and support
- The percentage of clinics who ask patients whether they would like to register their interest in participating in research rose from 73% in 2013 to 85.4% in 2014
- MSNAP membership increased from 33.7% to 47.2%

The key recommendations made in the report were:
- Resources should be allocated appropriately to memory clinics to ensure that all those who need it receive timely assessment, diagnosis and high quality follow-up care
- Consideration should be made as to why substantial variation occurs in funding for services
- Length of wait from referral to first assessment is too great in some areas and needs to be addressed
- CST is an intervention recommended by NICE and all memory clinics should aim to provide or gain access to this therapy

P4.2. **The use of ICT for the assessment of people with dementia and mild cognitive impairment within the Dem@care project**

**KÖNIG Alexandra**

**Introduction:** Currently, the gold standard for the assessment of cognitive and functional abilities involves questionnaires and clinical rating scales. However, these are often limited in their ability to provide objective and sensitive information. In contrast, information and communication technologies (ICT) may overcome these limitations by capturing more fully the disturbances associated with Alzheimer disease (AD). We investigated the use of different sensors, such as an accelerometer, video monitoring system or audio analyses for the assessment of people with dementia and mild cognitive (MCI) impairment.

**Methods:** Three groups of participants (healthy control, Mild Cognitive Impairment and Alzheimer’s disease) in two different Memory Clinics (France and Greece) had to carry out a standardized scenario consisting of directed tasks (single, dual task and vocal tasks) and activities of daily living such as preparing pillbox while being recorded. The performance quality of each participant was manually annotated and assessed based on the amount of successfully carried out tasks. Recorded data was processed by a platform of signal analysis in order to extract parameters detecting activities undertaken by the participant. We developed a classifier based on the extracted
features for diagnostic prediction and further autonomy performance prediction. Furthermore, in order to analyse the recorded data from all the sensors, we employed knowledge-driven interpretation techniques based on Semantic Web technologies.

Results: Overall, activities and task performances were detected automatically with high accuracy rates (up to 80%). Further detailed results from the audio, gait and video analyses as well as results from a comparative analyses between the two clinical settings will be presented at the conference.

Conclusions: The results suggest that it is possible to assess people with dementia and MCI autonomy with the help of ICT and in particular, an automatic video monitoring, audio analyses and accelerometers and that the use of such technologies could provide clinicians with diagnostic relevant information and improve assessment in real time decreasing observer biases.

P4.3. You are happy and safe: a discourse analysis of a diagnostic disclosure of dementia

OYEBODE Jan, ZUHURA Muhamed

Background: Retrospective accounts have found that most people with dementia wish to know their diagnosis although many report that diagnostic disclosure was not well managed. Information from real-time recordings has potential to reveal more about how disclosure of the diagnosis is negotiated.

Aims: Our principal aim was to explore the way the meaning of dementia was co-constructed by clients, carers and practitioners in the appointment in which the person was given their diagnosis.

Method: Audio recordings of eight diagnostic feedback sessions, delivered by a range of health professionals, were analysed using discourse analysis, considering how language was used to co-construct meaning, perform social functions, position the ‘actors’ and distribute power.

Findings: Carers, clients and practitioners constructed dementia as largely a memory problem. This frequently caused confusion and at times the professional had to undertake repair work to amend this (mis-) understanding. Professionals sometimes appeared to incorporate clients’ and carers’ perspectives but analysis indicated this was often merely a rhetorical strategy, used to satisfy the client that they were being heard. How and when the diagnosis was given depended on what clients and carers said and how much resistance they showed to accepting the news. Professionals preferred to adopt the identity of deliverer of good news and avoided the identity of bearer of bad news. By positioning themselves as guardians of clients’ rights, those with dementia were sometimes positioned as frail and incapacitated.

Conclusions: Practitioners still find it difficult to give a dementia diagnosis, sometimes leading to confusion and disempowering of those with dementia. Nonetheless, the process can be constructive and provide the individual enough space to co-construct a satisfactory meaning around their diagnosis. Therapists can help widen the subject positions available to people with dementia, to help them understand their diagnoses in a way that leads to positive psychological outcomes.

P4.4. Leveraging volunteers in retirement communities to increase diagnosis of dementia

MORGAN David, BANK Jessica, POILEY Eileen

Less than half of older adults with dementia do not have a formal diagnosis. Screening for possible memory impairment may assist in increasing the rate of diagnosis. In the state of Florida, there are a number of retirement communities where all residents are 55 years or older. The Villages, a Florida community of 100,000 55+ residents has partnered with the University of South Florida to improve community health. One request was to provide free memory screening for the Villagers. To meet this request, we developed a training program to teach retired health care professionals to deliver and score the Montreal Cognitive Assessment (MoCA), a 20-30 minute test of memory and executive function. Volunteer training consists of 3 sessions. Those volunteers who master the process set up appointments to test the memory of community residents, typically testing four residents over 2 hours. A procedures manual for this training was developed so that other organizations may leverage volunteer efforts to increase awareness and diagnosis of dementia. Individuals who score well on the MoCA are advised to return after one year for re-evaluation. Individuals who score poorly (about 20%) are advised to seek more detailed evaluation by medical dementia specialists. Individuals opting to learn about clinical research opportunities are entered into a Memory Care Registry. When clinical research opportunities are identified for which they might qualify, they are contacted with information about the study in the event they wish to participate. This program is being performed in other retirement communities or areas with a high concentration of older adults in Florida. The goal is that older adults should have access to free memory screening and that the number of older adults with dementia lacking a medical diagnosis should decline.

P4.5. Specialist nurses should form part of the post-diagnostic care and support network for living well with dementia

RAHMAN Shibley, SWAFFER Kate, GORDON Peter, MANES Facundo, MARSTERS Lucy Jane

Objectives: There have been numerous concerns that the health and care system in England is too fragmented, and lacks sufficient focus for a person with dementia or caregiver to navigate through the system. This makes it difficult for people to live well with dementia. The aim of this study was to conduct a preliminary online survey into citizens’ attitudes to what post-diagnostic support in the English jurisdiction could look like.

Methods: 90 respondents completed the online “Survey monkey” survey, invited from a Twitter account with around 13000 followers. The survey could only be completed once. Participants were invited...
to be a person who had just received a “timely” diagnosis of dementia in the English jurisdiction.

**Results:** You were most likely to see your General Practitioner if you were aware of dementia and had noticed memory problems (49%) rather than simply talk to friends and family (33%), but you were likely to take action as soon as possible (92%). You were most likely to wish to have follow up from a neurologist and community psychiatric nurse (39%), with input from a specialist nurse in a multidisciplinary team (74%). However, you would (just) prefer to have a specialist nurse as your ‘care coordinator’ (47%) rather than a “dementia adviser” (34%), but to have a primary caregiver’s input in formulating a personalised care plan (46%). (Respondents further stated that the decision to implement clinical nursing specialists should be based on clinical outcomes (76%).)

**Conclusion:** The results from this preliminary survey identify the clinical nursing specialist as key stakeholder of future importance in the English jurisdiction, working together with a person living with dementia and the primary caregiver in the post-diagnostic care and support network. This will vastly improve likelihood of living well with dementia.

### P5.1 Building dementia friendly communities - sharing the learning from the independent evaluations of York and Bradford

**HARE Philly**

York and Bradford, though both cities in Yorkshire and only 60 kms apart, are very different places — with different histories, resources and cultural make-up. The approaches they have taken to build DFCs are also quite different.

The presenter is Philly Hare, Programme Manager for JRF’s Dementia without Walls programme. She will start with a very short film (2 minutes) about DFCs, featuring a York couple affected by dementia, and their local dementia friendly cafe. This will set the ‘human tone’ and emphasise the centrality of people with dementia in DFCs. Philly will then summarise the key findings of the evaluations and draw out the learning points. These will include learning on:

- Bottom-up or top-down?
- Enabling ‘a thousand flowers to bloom’; the role of small grants and local ‘champions’
- The role of the local authority
- The principle of inclusion
- Reaching out to the most marginalised groups (e.g. local BME and LGBT communities)
- The meaningful involvement of people affected by dementia (with specific examples)
- The power of networks: dementia action alliances and the national involvement network (DEEP)
- Local impact
- The future: commitment, investment and sustainability

The session should be of interest not only to policy-makers and professional practitioners, but also to people affected by dementia, community activists and event the general public. The overall aim of the session is to share learning (both positive and negative) with those engaged (or planning to be engaged) in similar endeavours.

We hope that they will leave encouraged and informed with plenty of practical ideas of how they can move forward in their own localities, based on our learning about what works best.

### P5.2 Dementia friendly America: a private-public partnership to foster living well with dementia in U.S. communities

**MASTRY Olivia, CLARK Alex**

A cross-sector collaborative of national organizations and individuals living with dementia have organized to advance a Dementia Friendly America. We are building on the Minnesota model, ACT on Alzheimer’s (See, http://actonalz.org/communities-action-resources previously presented at Alzheimers Europe) to offer a national resource and technical assistance process to engage communities in becoming dementia friendly. The collaborative is uniquely positioned to leverage change and achieve spread because its members can activate their state and local affiliates from health, long term care, financial services, legal, business, faith, federal and state government, law enforcement, cultural community networks and Alzheimer's disease and aging organizations. The collaborative goal is to improve quality for life for people living with dementia in community and their care partners by offering a national resource and technical assistance tools by first quarter 2016 and pilot and evaluate geographically and culturally diverse communities across the U.S. An evaluation will set goals for and measure success against agreed upon indicators including:

- Improved quality of life for persons living with dementia and their care partners
- Increased awareness of and confidence across community sectors in supporting persons with dementia and care partners
- Increased dementia-friendly services and practices
- Increased rates of detection/diagnosis and referral to community supports

This initiative is unique worldwide in that it is privately rather than publicly run (although government agencies are actively involved). Individuals living with dementia and their care partners are instrumental in shaping and guiding the effort.

The presenters will present:

1) A brief overview of the comprehensive collaboration;
2) The dementia friendly resources used in the initiative and the overall research basis for the four phase approach;
3) Instruction on how to use the resources in any community
4) Case studies to show how the Toolkit is being implemented in distinct pilot communities;
5) Evaluation plans and progress to date.
P5.3. Dementia friendly communities: an integral approach facilitated by higher education

SMITS Carolien H.M., GROEN-VAN DE VEN Leontine, VISSEER Geraldine

Introduction: A dementia friendly society is meaningful to all participants. Such a society requires collaboration between partners in the public, private and profit domain. Participation of people with dementia and their relatives contributes to meaningful results. An integrated approach addresses both the social and physical domain of society. So far we do not know how (higher) education may contribute to a dementia friendly society.

Methods: We piloted six interventions from an integrated, participative perspective: (a) positive views of dementia (b) a swimming programme for people with dementia and their carers (c) a dementia friendly hospital (d) dementia friendly local policies (e) the Dementia Shop (f) simulation kit dementia 24/7. Bachelor students (applied gerontology and nursing) facilitated and evaluated these pilots. They were supported by lecturers and researchers. A sounding board of older adults reflected on the aims and structure of the projects.

Results: Students, lecturers and researchers contribute to a dementia friendly society by facilitating and evaluating innovative projects. Participants appreciate the activities of students. Students enjoy participating in dementia friendly projects. Their progress benefits from (1) innovative and creative interactions (2) interaction with a variety of participants: people with dementia, their family carers, students, lecturers researchers, care professionals and policy makers.

Conclusion and Practice implications: Higher education can contribute to a dementia friendly society. Universities of Applied Sciences should invest in involving students in creative and innovative projects. Interaction with people with dementia may help take away negative stereotyping.

P5.4. Dementia Friendly Society - Living in the community

MAPES Neil

Risky Business “Supports staff and volunteers to feel more confident in using a balanced approach to risk-benefit assessments” This approach will then help ensure that life with dementia is worth living and is connected to both nature and a sense of adventure.”

People with dementia have the right to live a full life connected to the people and places they love and that keep them well. Since 2009 the national dementia strategy for England “Living well with dementia” invited us all to rethink the way we responded to the challenge of maintaining a good quality of life for people with dementia and their families. A new generation of people are now living with dementia and a new generation of staff are supporting them. We believe that regular contact with and connection with nature is an integral part of what it means to ‘live well’. We also believe that taking risks is a key feature of living well. Often people living with dementia have limited choices in their lives or live in care situations with over-protective cultures leading to many people being safe but desperately unhappy. Risks do need to be carefully assessed and managed but an analysis of risks is only half the story. We must also equally examine the benefits of the activity we are undertaking. We must also think differently about the possible choices on offer to people with dementia and ‘expand our horizons’ when thinking about introducing new activities and services. Only then can we support people living with dementia to thrive and have a sense of adventure in their lives.

Neil will present the positive benefits of the ‘Risky Business’ approach and a person with dementia will show a film of their experience and tell their own story.

P5.5. Towards dementia friendly community with Alzheimer Café

LUKIČ ZLOBEC Štefanija, KRIVEC David

We received the information about Alzheimer Cafe in June 2012 at the Alzheimer Europe lunch debate meeting in Brussels. Our colleagues from Netherland provided us with the manual for Alzheimer Café. We have immediately started to work on the subject together with dr. Aleš Kogoj (psychiatrist) and Bojanka Genorio (director of Nursing home Fužine).

We have organized the first Alzheimer Café in Slovenia at Nursing home Fužine on 23. June 2012. The event was widely promoted in media. In addition to the family members and carers of persons with dementia, we invited journalists from all the relevant local and national media and others working or interested in this field. Already the first Alzheimer Café was a success! It turned out that in Slovenia we need such support groups meetings for families. Alzheimer Cafes quickly spread across Slovenia, now there are already more than 60 different locations for our country. Every event is widely promoted in national and local media to reach wide visibility of the subject and raise the awareness about dementia. With this publicity, we contribute to the destigmatisation of dementia and to Dementia friendly society.

The idea of Alzheimer Cafes is to organize gatherings of persons with dementia, their relatives, carers, friends and dementia experts and representatives of local association in a public place with a relaxed atmosphere like bistro, café, library. At each Alzheimer Café we have a presentation of a dementia related topic by an expert (health or social worker) or Spominčica representative, followed by a discussion and socializing. At these gatherings, participants are informed and educated about dementia, exchange information and experiences, talk with others and socialize. Besides the informative and social aspect, Alzheimer Cafes have a significant role in raising awareness about dementia.

P6.1. Overcoming Alzheimer’s stigma: using a mediatised event to create an awareness campaign

WILLIAMS Kate, NICAISE Salomé, PALERMITI Federico

Context: According to Moroccan authorities, in 2020, people aged 60 and over will represent between 11 and fifteen percent of the Moroccan population. The number of cases of dementia and other related disorders in Morocco is currently estimated between 70,000
and 90,000. This number is extremely under-estimated due to the fact that there is still a tremendous stigma attached to dementia. This negative perception of the disease creates a taboo, and dementia is often associated with insanity and even witchcraft.

Objectives: During the 2015 edition of the emblematic automobile rally “Rallye Aicha des Gazelles”, the Monegasque Association for research on Alzheimer’s disease (AMPA) and the South Morocco Alzheimer Association (SMA) organised 2 initiatives in the framework of the Mediterranean Alzheimer Alliance (MAA). For the 1st time a team “Les Gazelles pour Alzheimer” participated in this competition in the name of dementia awareness. For the 1st time an Alzheimer caravan was also organised during the rally in order to distribute information and provide support in some of the isolated villages in Morocco. These two simultaneous initiatives are a perfect example of how to convey a positive message and raise awareness on dementia using a mediatised event.

Results: The Alzheimer caravan provided specific dementia training in 7 villages and more than 500 information pamphlets in Arabic and in French were distributed. Neurology consultations were proposed and medication was sometimes offered. Trained staff were able to talk openly to families about dementia and its consequences - a first step forward in changing the perception of this illness.

Concerning the automobile rally, competing for this cause gave “Les Gazelles pour Alzheimer” added motivation to complete the rally. The excellent press coverage during the competition was an amazing opportunity to create a true awareness campaign for dementia.

P6.2. Perceptions of memory-friendly Finland from parliamentary election candidates

POHJANVUORI Anita, OKKONEN Eila, KUUSTERÄ Kirsti

The candidates in parliamentary election could be seen as a smaller version of the Finnish population – they come from different backgrounds and from every part of Finland. During the spring 2015 The Alzheimer Society of Finland invited all the 2000 candidates to support an election pledge towards “memory-friendly Finland”, and the candidates responded positively. As a part of signing the pledge, the candidates stated their own reasons to sign it. These explanations form a rich data that offers glimpses to the perceptions and images of memory diseases and the concept of memory-friendliness.

The candidates (currently n=424, but the campaign runs until mid-April) signed the pledge in a website (www.muisti15.fi) and were able to share their involvement through social media. The invitations to join the campaign were sent via email to most of the candidates, but the candidates were also reached through local happenings and social media. Thus it can be assumed that the candidates have an interest to publicly support the cause and are inclined to have positive attitudes towards memory diseases.

The election candidates’ perceptions of memory-friendly Finland are examined through qualitative content analysis. According to the preliminary results, the candidates’ explanations to sign the pledge can be divided into three major category: 1) personal experience,

2) memory diseases as a national health issue, and 3) human right approach.

Part of the data consists of the ways the candidates describe how they would as members of parliament support the construction of “memory-friendly Finland”. According to the data the “memory-friendly Finland” will be built based on elements such as: 1) prevention of memory diseases, 2) investing in good care, 3) paying attention to the families and informal caregivers, and 4) supporting research and development.

These results will be revised and developed after the campaign ends in April.

P6.3. Coming Out of the Shadows

LEONARD Tina

“People don’t have to be afraid and people don’t have to be awkward about it, it is also not a reason for us to declare our lives over, with the correct supports we can continue to live long in the community.” Ronan Smith, member Irish Dementia Working Group.

The stigma attached to dementia can prevent people from talking openly about it and there is a growing body of work that suggests that stigma promotes social exclusion (Alzheimer Disease international, 2012), having a similar impact to the widely accepted experience of living with a physical disability (Alzheimer Australia, 2010). As a result the person can withdraw from social situations for fear that others will find out; stigma therefore poses an obstacle to the well-being and quality of life of both persons with dementia and their family carers (ASI, 2006).

This presentation outlines work undertaken in Ireland to bring dementia “out of the shadows” by challenging commonly held perceptions and by changing the visual narrative used in the portrayal of dementia. Two public awareness campaigns run by the Alzheimer Society of Ireland (ASI) addressed stigma around dementia, by placing the person and their carer at the heart of the campaigns to ensure their voices were heard and their faces seen.

The presentation will describe the content of these campaigns, including visual and audio examples and images. These will be compared to more “traditional” images of dementia. The impact of the campaigns and their continued “life” via ongoing media work will be discussed with evidence presented on the reversal of previous negative trends and the positive impact on social and traditional media as well as increases in demand for dementia specific services as a result of the campaigns.

P6.4. Dementia Friends – Changing the way a nation acts, thinks and talks about dementia

HUGHES Jeremy, CROWTHER Nikki, RODRIGUEZ Natalie

Dementia Friends aims to provide people with a better understanding about dementia and the everyday, practical actions they can each take. Having already achieved our goal to reach one million people with this information, understanding and empathy by 2015, a further
P6.5. Living well with dementia: changing perceptions & images of dementia

MacDONALD Anne, Scottish Dementia Working Group

Background: The Scottish Dementia Working Group (SDWG) is a national campaigning group, run by people with dementia and is the independent voice of people with dementia within Alzheimer Scotland. The Working Group campaigns to improve services for people with dementia and to improve attitudes towards people with dementia.

Aims: This project, which we are presenting, is focused on novel ways of highlighting and challenging some of the negative stereotypes of dementia and thereby reducing the associated fear and stigma.

The SDWG believes that negative representations, particularly in the media, serve to sensationalise aspects of dementia and perpetuate a culture of fear surrounding dementia and are committed to working to change the way in which people with dementia are viewed by reducing the prejudice and stigma that can affect people with dementia negatively.

Method/Participants: Six group members have recently become involved in “Keeping Track” a national project being facilitated by RADAR, a media development and citizen journalism organization. Using specially adapted handsets, a communications channel has been created to enable people at the early stages of dementia to voice record details about the impact of the condition in their own words. Through this, participants are being given a unique opportunity to develop "Dementia Diaries" and share their personal experiences, in order to increase public understanding about dementia, tackle stigma and improve support services.

Findings/Desired Outcomes/Conclusions: The “Dementia Diaries” were featured in the Comic Relief Twitter Takeover on 26th February 2015. The dedicated Twitter feed created opportunities for people to share the realities of living with the illness and to raise the profile of the issue in the UK. One of the SDWG committee members made a contribution on “Living Well with Dementia” for the comic relief site, and the feature was picked up in the national newspapers.

P7.1. Decision-making in dementia care: autonomy, capacity, and the legal doctrine of "informed consent"

DAVIDSON Hope

While the principle of ‘patient autonomy’ in healthcare decision-making, expressed through the legal doctrine of ‘informed consent’, represents an advance in terms of patient rights for ‘capable’ adults, it has no application for so-called ‘incapable’ adults - such as those with more advanced dementia. In practice, once deemed ‘incapable’ of making a decision the family or carers of a person will often give consent. There is however, no legal protection for the giving of consent in this way, and there is no provision for ensuring that the wishes and preferences of the person are factored in to any decision to be made.

The law relating to capacity is currently being reformed in Ireland, along with many European jurisdictions, with the aim of supporting and assisting ‘vulnerable’ adults, including those with dementia, to make decisions for themselves, but it remains premised on a narrow capacitated/ incapacitated divide, with those passing a functional capacity test being permitted to make their own decisions and those who do not, not.

Recent jurisprudence from the European Court of Human Rights, suggests that it has become necessary for the law to look beyond capacity, and to address in terms of human rights, issues of voluntariness and understanding. In Shukturakov v Russia the Court found that while the applicant lacked ‘de jure legal capacity to decide for himself’ that this did not necessarily mean that he was ‘de facto unable to understand his situation’. What this means then, is that while a person with dementia may not be in a position to give a legally binding consent, that this does not mean that their rights to be involved in the decision-making process do not need to be protected. The singular challenge then is how the current ‘informed consent’ process might be enhanced or adapted to incorporate these essential rights.
P7.2. Promotion of legal rights of people with dementia in Portugal

ZINCKE DOS REIS Maria Do Rosário

The United Nations Convention on the Rights of Persons with Disabilities was ratified by Portugal in 2009 and subsequently included in its national law. The purpose of this Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. It states that “persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”.

Furthermore, it stipulates that “States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.”

In Portugal, an individual who lacks mental capacity may be declared either subject to interdiction or incapacitation according to the degree of incompetence. If interdiction is granted, the subject will be considered as incompetent to make any personal, health, property or financial decision. The legal process is very slow and expensive and there is significant lack of awareness on the importance of appointing a guardian that will have the duty to promoting the rights of the person with incapacity. Moreover, there are no professional guardians and no possibility of choosing a guardian in advance when the person is still capable. As a result, there is a considerable number of people with incapacity but no guardian, currently being cared by their families that may act in good faith but with no legitimacy to act on their behalf. To compound this problem, there is a growing number of people with mental incapacity who are living on their own in poor conditions (lack of food, hygiene, home) because there is no one to be appointed for their protection or to act on their behalf. It is only lately that Portugal initiated proceedings to answer Article 33 of the Convention through the launch of a committee to which representatives from several patient organizations will form part. It is hoped that this is a right step forward towards a new legal framework that really promotes and respects the rights of people with dementia and other forms of disability or incapacity.

P7.3. Self-determination or protection - pitfalls of the guardianship system

NIKUMAA Henna, KOPONEN Elina

As a part of a project of Society for Memory Disorders Expertise in Finland 94 professionals were interviewed in 24 group interviews. The participants were from different social and health care units, legal aid offices, banks, local register offices and from the third sector. The primary aim of the interviews was to map out the problems and challenges in the field of legal rights of people with memory illness. One topic was the challenges in the public guardianship services. The fundamental question in the interviews was how to find an appropriate balance between self-determination and protection of the person with memory illness. Based on that question, the participants reported many different pitfalls in the public guardianship system. The first problem pointed out was that most of the people recently diagnosed with memory illness do not consider later life planning relevant at the moment, which usually leads to a situation in which their legal capacity has already weakened to the point where planning is no longer possible. Means of later life legal planning, such as advanced directives or continuing powers of attorney, are still unfamiliar. Secondly the participants reported how applying for guardian doesn’t target the right way. There are still misunderstandings that every person with dementia needs a guardian. It is not made clear that only when a need for proxy decision making emerges, and no milder option or measure is enough to secure the person’s rights, applying for guardian becomes current. On the other hand, people may delay applying and questionable legal acts are possibly made in the meantime.

A third obvious pitfalls referred to the application process. It is not clear for people with memory illness, or their carers or even for social and health care professionals, how the application process starts. Other pitfalls were related to incorrect assumptions of the guardian’s tasks and to the lack of cooperation between different entities and units.

P7.4. Protecting people who cannot consent to their admission in a nursing home. Recent evolutions in the French law

COQUELET Alice, GZIL Fabrice

Legal provisions relating to the attendance in nursing homes, and to restrictions of freedom of movement are crucial issues for the respect of the rights of people with dementia (PwD). As shown by the comparative study of European legislations conducted by Alzheimer Europe in 2011, the way to deal with these issues differs considerably between countries. In addition, existing provisions are sometimes considered unsatisfactory and reforms are being discussed, e.g. in France and in the UK.

In this presentation, we will consider the recent evolutions of legal provisions relating to involuntary attendance and to the use of
coercive measures in French nursing homes. After a brief history, we will study and discuss the provisions debated in French Parliament, in light of the amendments proposed by Fondation Médéric Alzheimer. The legal provisions that should frame the attendance of PwD and the use of restrictive measures in nursing homes have been a matter of debate in France for more than 10 years. The model of involuntary commitment in psychiatric wards was considered, but excluded. Finally, legal provisions should come into force in 2016. This is an important move, as measures affecting the fundamental right of freedom of movement are not uncommon in practice, and occurred in a kind of legal vacuum.

However, French law makes it very difficult to consider the situation of people legally capable, but unable to understand the issues and outcomes of a decision. This leaves people who are unable to give informed consent to their admission in a nursing home, or to measures restricting their freedom, without adequate protection of their basic rights. If the choices made by the French Parliament provide at last a legal framework, they will not provide all the safeguards necessary to guarantee the fundamental rights of PwD to be recognized and protected.

P7.5  Legal & ethical issues around freedom to roam for people with dementia

GRAY Patrick, PASCOE Ann, SHEFFIELD Ian, WATT Catriona

To show how the debate around ‘tagging’ people with dementia to ‘allow’ them to be ‘safe to wander’ has raised the importance of legal and ethical issues and how people with dementia do not want to feel ‘tagged, but rather want ‘freedom to roam’. How risk aversion is a contributing factor to people with dementia not being able to roam as they wish and how a key issue that Dementia Friendly Communities CIC grappled with was, who has the legal and ethical right to decide when a person with dementia may wear a GPS tracker.

How, despite the fact that laws on incapacity may differ between various countries, the fundamental principles of the European Convention on Human Rights (ECHR) remain the same which means the legal and ethical issues around freedom to roam safely rest only on human rights’ points of view. How this has informed the Scottish Mental Welfare Commission.

How using a GPS tracker should be used when the person with dementia is at real risk of being lost or is at risk of harm and in danger, and NOT simply to check up on them, that anything done should be in the best interests of the person with dementia and be the least restrictive of their rights and freedoms.

How any person with dementia should be entitled to live their life freely and how this can be done by balancing their wish to go where they choose and associate with whom they choose with the risk of harm – including the many risks arising from becoming lost – from doing so.

P8.1  Allied health professionals: connecting people connecting support

HUNTER Elaine

Background: Allied health professionals have the expertise to support people with dementia, their families and carers to live well with dementia (Scottish Government 2012). The role of the author focuses on bringing the skills of this group of professionals to the forefront of dementia practice and linking their therapeutic skills to the needs of people with dementia and their families.

Aims: To share the expertise of allied health professions we developed leaflets and publications whilst also looking to social media. We looked beyond the traditional boundaries to share their knowledge and considered social media which is growing in influence (Holdsworth et al 2013)

Methods: In June 2104 we launched a weekly blog called “Let’s Talk about Dementia”. (www.alzscot.org/talking_dementia) hosted and supported by Alzheimer Scotland and led by the author, an allied health professional. The blog shares the practice of allied health professionals focusing on a range of topics from diet, physical activity to keeping engaged with your community. The contributors are practicing clinicians, staff from Alzheimer Scotland, students and academics. Within the blog there are links to resources, video content and comments are encouraged.

Key Findings: In the first eight months we had
- 21,760 hits from 40 countries
- 323 people receiving the blog by email
- An understanding the top areas of interest were falls prevention, an enabling home environment, communication tips, work and dementia
- 263 interactive comments from people living with dementia, carers and professionals

Conclusions: Through the blog the expertise of allied health professionals is accessible and the reach of the information is international. Importantly we are connecting to people living with dementia and their families creatively and innovatively. The blog offers allied health professionals a new way to connect to people with dementia and their families, providing a platform for individuals to voice their views and share ideas.

P8.2  Assessment and follow-up by dementia teams - the Norwegian Dementia plan 2015

MICHELET Mona, ENGEDAL Knut, SELBÆK Geir

Background: The Norwegian Dementia Plan 2015 was launched in 2007. One of the aims was to organize dementia teams or dementia coordinators in primary health care in all 428 Norwegian municipalities, in order to assist family doctors in diagnosing persons
suspected of having dementia and to provide post-diagnostic support to patients and family carers.

To evaluate the work we did a survey among 190 teams/coordinators, which had been in action for one year or longer. The topics were organization, routines and time used for assessments, different types of follow-up and other activities. Each team reported medical information about three patients they had recently assessed.

**Results:** Only 65% of the dementia teams/coordinators had assigned time for their dementia-specific work. The typical team consisted of 3-4 experienced registered nurses, occupational therapists or other health care professionals. Cooperation with family doctors, and these doctors’ knowledge on dementia was reported as challenging, although 38% of the patients were referred to the teams by their family doctor. The mean time spent per year on follow-up per patient and their carers was 5 hours.

The persons assessed had a mean age of 81 years, 63% were females and mean scores were: MMSE 20.4, Clock drawing test 2.8 of 5 points, IQCODE 4.2 and Cornell scale for depression in dementia (CSDDD) 8.6 points. However, only 41% of the assessments included the CSDDD. The carers scored a mean of 19.3 points on the Relative’s Stress scale but only 52% of the carers had filled in this scale.

**Conclusion:** The dementia teams express that they will need more resources to fulfil their tasks in the future. Future assessments by dementia teams need to be more complete and there should be more focus on follow-up. Increasing the knowledge of dementia among family doctors should be a priority in the future.

**P8.3. Post diagnostic support in dementia – the contribution of the allied health professionals in Scotland**

GROAT Alison

**Background:** There are approximately 90,000 people living with dementia in Scotland. Within Scotland’s National Dementia Strategy (2013-2016) there is an emphasis on the importance of post diagnostic support. It is recognised that the Allied Health Professionals (AHP) National Delivery Plan, 2012 have the expertise to support people with dementia, their families and carers to live well with the condition, however we had no national overview of what was currently happening in this area.

**Aim:** The work set out to develop a national survey to enquire about the current contribution of the AHPs in relation to post diagnostic support in dementia. The scoping exercise also aimed to understand the links between the Alzheimer Scotland Dementia Link Workers (who are involved with people for a minimum of one year post diagnosis) and the AHPs.

**Method:** A Consultation Group was formed with AHP Leads from the Health Boards across Scotland. Engagement took place with key stakeholders and a literature review was carried out. This informed the Link Worker and AHP surveys. Follow up interviews with 16 participants was also part of the process.

**Key Findings:** Key findings will be presented and include:
- There is a lack of clarity around the role of, and the referral process to, the AHPs working in post diagnostic support
- There are variable links between the AHPs and the Link Workers
- Partnership working produces benefits for people with dementia and carers

**Conclusion:** The initial findings will be published outlining recommendations on the way forward. We are now developing a change programme to improve access to Allied Health Professionals for both the Alzheimer Scotland Link Workers and people living with dementia. The aspiration is that having access to this expertise in the first year will enhance the ability of people with dementia to live well within their own homes.

**P8.4. “Work keeps me well”: the benefits of continued employment following a diagnosis of dementia**

RITCHIE Louise, TOLSON Debbie, DANSON Mike

It is estimated that there are around 38,000 people of working age (under 65) with dementia in the UK. Given the current emphasis on early diagnosis and the increase in state pension age across Europe it is likely that the number of people in employment when diagnosed with dementia will increase. Drawing on the active ageing literature, this paper aims to explore the potential benefits of supporting continued employment for people with dementia in terms of health, social and psychological wellbeing. The study adopted a qualitative approach using case studies (n=15). Each case study is based around a person aged between 50 and 66 with a diagnosis of dementia or mild cognitive impairment and who is still in employment or had left in the last 18 months. Case studies involved interviews with the person with dementia, a family member and a workplace representative and analysis of relevant documents. Of the 15 case studies, eight people with dementia continued paid employment post diagnosis and seven were retired due to ill health at the point of diagnosis. A cross case thematic analysis was conducted to explore similarities and differences in the experiences of case study participants. The results show differences between the experiences of people who continued employment post diagnosis and those who retired due to ill-health. Reflecting on the experiences of participants, the themes to be presented include ‘work keeps me well’; ‘identity as a worker’; ‘leaving work’; ‘family dynamics’ and ‘workplace perspectives’. Overall, the results show that continued employment can have a positive impact on the lives of people with dementia and their family. This will be discussed in terms of the implications for post diagnostic support, employment policy and support in the workplace. The importance of appropriate support for leaving employment and adjusting to retirement in situations where continued employment is not possible will also be highlighted.
P8.5. Advance directives and dementia – Perspectives from people with dementia and their informal caregivers

SCHMIDHUBER Martina, SCHALLER Sandra, FREWER Andreas, KOLOMINSKY-RABAS Peter

Objective: Advance directives aim to support the autonomy of people with dementia. The person without dementia can define how she/he would be treated in the case of dementia. However, what do people with dementia and their relatives know about the possibilities and boundaries of advance directives? We want to present the first results of a survey in the European Metropol Region Nürnberg (Germany).

Methods: In face-to-face interviews with open and structured questions, focusing on the possibilities and boundaries of advance directives, we identified the level of knowledge of people with dementia in early stage and their informal caregivers. We asked among other what they think about the significance of the advance directive.

Results: The first results from the pilot group are from 24 persons with dementia, aged 53 to 92 years, and their 24 informal caregivers, aged 31 to 81 years. Both, people with dementia in early stage and their informal caregivers are not always sure how binding the advance directive is. Nearly 12 % of them are not sure, if the physician is bounded on the directive (4 persons with dementia, 1 informal caregiver). More than 14 % of the persons do not know if the directive could be revoked (5 persons with dementia, 2 informal caregivers).

It is also doubtful for nearly 50 %, if they could make directives especially for the case of dementia (7 persons with dementia, 16 informal caregivers). Sometimes the opinions are wrong e.g. 7 informal caregivers think that it is not possible to revoke an advance directive.

Conclusion: Our results show that people are not always sure about the possibilities and boundaries of advance directives. More information and enlightenment is necessary to support the idea of advance directives: people's autonomy in the case of dementia.

The research is funded by: Emerging Fields Initiative (EFI), Friedrich-Alexander-University Erlangen-Nürnberg (FAU), Human Rights in Healthcare.

P9.1. The Hellenic longitudinal investigation of aging and diet (HELIAD): study description and preliminary data

MARGIOTI Eleni, SAKKA Paraskevi, DARDIOTIS E, KOSMIDIS MH, YANNAKOULIA M, HADJIGEORGIOU CM, SCARMÉAS N.

Background: Alzheimer's disease (AD) is a progressive, irreversible neurodegenerative disease that has been described as a rapidly growing epidemic of modern societies. In Greece, population-representative, recent data concerning AD prevalence and incidence of diseases of cognitive ageing are lacking. The Hellenic Longitudinal Investigation of Aging and Diet (HELIAD) is a population-based, collaborative, multidisciplinary study designed to investigate the prevalence and incidence of Mild Cognitive Impairment (MCI), AD, other forms of dementia and other neurodegenerative brain diseases in the Greek population over the age of 65 years. The study also aims to investigate correlations between cognitive function of the elderly and other factors, such as demographic, nutritional, social and environmental.

Methods: The study is being conducted in Larissa and in Maroussi-Athens. Community-dwelling individuals have been selected to participate in the study through random sampling from municipality registries. The study is prospective in design with planned reevaluation every 3 years.

Results: In total, 1900 participants have already completed the initial evaluation and 520 have been reassessed after an average of 3 years. According to data analyses from the first subgroup of 1050 participants, they were on average 73.4±6.0 years old, 60% of the sample were female, while most of the participants were poorly educated with an average of 5.41±3.5 years of education. Preliminary data relating to demographics, neuropsychological tests, medical history, dietary habits etc. concerning the full sample will be presented in the conference.

Conclusions: The HELIAD study may provide important data for expanding our knowledge regarding the prevalence, incidence and risk factors of dementia and several other neuropsychiatric diseases in Greece towards designing and implementing comprehensive and effective policies and strategies.

P9.2. Experiences of users in Ireland of an online intervention (In-MINDD) to support the implementation of lifestyle changes to reduce dementia risk: A qualitative exploration using Normalization Process Theory

PIERCE Maria, REDMOND Muriel, BROWNE Susan, WOOD Karen, POWER Kevin, O’DONNELL Catherine, IRVING Kate

Dementia is a serious loss of cognitive ability beyond what might be expected from normal ageing. Whilst dementia is incurable, a number of factors have been identified which can either enhance or reduce an individual’s risk of developing dementia. However, the links between dementia and modifiable risk factors are neither well known among the general public nor well addressed in primary care. In-MINDD (Innovative Midlife intervention for Dementia Deterrence), an EU FP7 funded project, seeks to address this. Using a Lifestyle for BRAin Health (LIBRA) model based on a systematic review and Delphi consensus study (Deckers et al., 2014), the In-MINDD profiler was developed to assess the presence or absence of modifiable risk factors for dementia and generate a personalized profile of person’s lifestyle for brain health. An accompanying online environment with information and supports was developed to assist individual’s adopt and adhere to lifestyle changes to promote their brain health and potentially reduce their risk of developing dementia in later life. A feasibility randomised controlled trial (RCT) was undertaken in Ireland, France, Scotland and the Netherlands to evaluate the
P9.3. Moderate to high intensity aerobic exercise in elderly persons with Alzheimer’s disease


Introduction: Exercise has the potential to improve cognition, functional ability and quality of life, but evidence is scarce regarding the effect of moderate-to-high intensity exercise in patients with Alzheimer’s disease (AD). This was investigated in ADEX, a single blinded multi-centre RCT in patients with mild to moderate AD.

Methods: Two-hundred community-dwelling elderly persons with mild to moderate AD (MMSE score >19) were randomised to a control group receiving usual care and an intervention group receiving 16 weeks of supervised exercise (one hour three times/week, moderate-to-high intensity aerobic exercise, intended intensity of 70-80% of heart rate reserve). An extensive battery of cognitive tests, scales for neuropsychiatric symptoms, and quality of life were administered. Primary outcome was change from baseline in cognitive performance estimated by Symbol-Digit Modalities test (SDMT) in the intention-to-treat (ITT) group.

Results: One-hundred and ninety patients completed the study (mean age 71, range 50-89 years, mean MMSE-score 24, range 22-27). The ITT analysis showed a significant difference in the Neuropsychiatric Inventory in favor of the intervention group. No significant difference between intervention and control group was found in SDMT but in subjects who adhered to the exercise protocol, we found a significant effect on SDMT in favor of the intervention group.

Conclusion: This is the first completed large RCT on moderate to high intensity aerobic exercise in mild AD. Exercise appears to reduce neuropsychiatric symptoms in persons with mild AD, with additional benefits of preserved cognition in a subgroup of persons with high attendance and intensity.

P9.4. Participation in leisure activity to prevent later life cognitive decline: a systematic review of literature

FALLAHPOUR Mandana, BORELL Lena, LUBORSKY Mark, NYÇÅRD Louise

Later life cognitive decline imposes restrictions in participation and dependence in everyday life on those afflicted, as well as burden of care on family and caregivers, healthcare professionals and requires considerable resources from society. Given the priority to the preventive strategies against later life cognitive decline, a large number of empirical studies have examined the link between participation in leisure activities and later life cognitive decline. This study aimed to describe the state of knowledge of the definition, categorization and operationalization of leisure activity in the empirical research that focused on preventing dementia. The analysis focused specifically on how leisure activity, dose effects and subjective aspects of leisure activity were operationalized as well as on the findings of the empirical research that focused on preventing dementia, and on discussing implications for occupational therapy. A systematic search was performed in different online databases for years 2000 to 2011, identified 52 publications for inclusion. Findings were discussed using the Model of Human Occupation and factors that might contribute to associations between participation in leisure activities and prevention of cognitive decline. The findings show that participation in leisure activities might significantly contribute to prevention of later life cognitive decline. However, important limitations were detected in terms of a lack of theoretical underpinnings, and little consensus and standardization in measuring key variables. The study reinforces the critical need to overcome these limitations to enable health care professionals to make evidence-based recommendations for increased participation in activities as a means of promoting health and preventing cognitive decline.

P9.5. The voluntary action of universal prevention of dementia

HEBAR Karmen

The extract introduces intention, preparation, realisation and evaluation of the research with the topic of universal prevention of dementia, entitled: “With activities towards the quality of growing old”, carried out by a Students’ voluntary club at the Institute of AMS on The day for Changes. The action was carried out in a form of intergenerational socializing, with a participation of high school students, elderly people from the surrounding Homes for the elderly (Retirement homes), their companions and mentors of voluntary work at the Grammar school. With this action we wanted to raise participants’ awareness on dementia, as well as on its risky and protective factors. We wanted to encourage them to lead a healthy lifestyle (in a social, mental and physical way), since the latter can be a protective factor for dementia. The intention of the initiative was also a stimulation of the youngsters to a prosocial behaviour towards tolerance and empathy, and to
minimise the presence of possible stereotypes or prejudices and at the same time, create an individual (with dementia) friendly society. Besides educational benefits and providing information about dementia and its risky and protective factors, this action was conducted in specific activities within workshops which, in a continuous implementation over a long period of time, can affect protectively or curatively in a milder form of dementia. In these workshops, the participants applied social and didactic games to train motor and orientation skills, social, visual, acoustic and physical abilities. We finished the action with tea and pastry and the evaluation of a meeting, in a style of “Alzheimer Café”.

After the evaluation of the action, the students showed larger awareness on dementia along with better knowledge of its protective and risky factors, as well as a high level of satisfaction with the directly gained experiences. Positive responses of all participants and their desire to organise such initiatives more frequently, have encouraged us to think about the repetition of the workshops. The action could be an example of a good practice for schools, particularly for those which include voluntary activities in their programmes.

P10.1. Enhancing the caring environment

COWAP Victoria, KNIGHT Karen

People living with dementia are likely to stay in an acute hospital three times longer than other people following admission and the longer people living with dementia are in hospital the greater the risk of an adverse event, e.g. dehydration, increased confusion and decreased functional independence. Consequently, in order to improve the experience for older people with dementia and to reduce unnecessary costs to the health and social care system, discharge from hospital must be as effective and timely as possible. The St Nicholas House step down unit was developed in a NorseCare Residential Care Home in Dereham Norfolk and has enabled an early discharge from hospital for older people with a cognitive impairment, but unable to return directly home or to longer term care. Quality of life improvements to residents are delivered through the:

- provision of a ‘home from home’ environment with a simple to understand building layout to support easy way-finding together with colour schemes that follow best practice guidelines.
- use of assistive technology to support and maximise independence which allow residents to rehabilitate further on their journey back to independent living.
- provision of communal spaces designed to a domestic scale with a ‘working’ kitchen and lounge/dining area in order to support residents to regain and maintain as many life skills as possible.
- availability of a visitors’ room to facilitate greater involvement of families and carers in the process.

The project has enabled staff to fully appreciate and understand best practice in dementia care and facilitated engagement with specialist community providers delivering a more ‘joined up’ approach to dementia care.

This project was made possible by the funding available through the Department of Health Dementia Capital Programme: Improving the environment of care for people with dementia.

P10.2. Getting it right for dementia – real solutions for improving hospital care

MCNAMARA George, TERRY Gavin, KANE Martina

Alzheimer’s Society’s annual report, Dementia 2015, published in July of this year, reports on how people are living with dementia, presenting the findings from our annual survey of people with dementia and their carers. This year’s report also has a special focus on people with dementia and their experiences of transition into, care within and discharge from hospital, in England. The issues around hospital care for people with dementia are well known, and include low levels of awareness amongst hospital staff of the specific needs of people with dementia, extended length of stay compared to admission for people without dementia who go in for the same procedure, delayed discharge and increased numbers of people with dementia being discharged to care homes.

The Care Quality Commission published Cracks in the Pathway in 2014, identifying widespread evidence of people with dementia being admitted to hospital when they do not need to be, and not being discharged quickly enough, with widespread variability in the levels of care that people with dementia received when transitioning from care homes into hospital and at time of discharge.

The work of the Dementia Action Alliance to produce the Right Care Hospital Charter aims to address the need to make hospitals and their workforces consistently dementia aware and dementia friendly. The recently launched John’s Campaign highlights the need for better involvement and recognition of carers whilst their loved ones are in hospital.

Unnecessary admissions and delayed discharge are both costly to the exchequer and have a negative effect on the quality of life of people with dementia. With the input of key experts in the field of hospital care for people with dementia, Alzheimer’s Society will develop solutions to these issues and how they should be implemented, integrating across health and social care provision.

We will look specifically at examples of best practice around transition into, care within and discharge from hospital and how they can be developed into wider practical guidance, capturing the essential elements that make them work, and identifying how and by whom they will need to be implemented to ensure that all aspects of hospital care for people with dementia and their carers improves.

P10.3. Impact of extended dementia care and dementia friendly environments to entire retirement homes

CHARRAS Kevin, REINTJENS Christophe

Introduction: Special Care Units (SCU) in retirement homes can only handle a limited number of people with dementia and/or related cognitive impairments, thus setting aside many people in need
P10.4. An evidence-based physical exercise protocol for people living with dementia in nursing homes

BRETT Lindsey, TRAYNOR Victoria, STAPLEY Paul, MEEDYA Shahla

Background: Physical activity has many benefits for older people but there is limited evidence evaluating the specific benefit for people with a dementia, in particular for those living in residential accommodation. This makes it difficult to determine the optimum parameters of physical activity for this population.

Aim: To present a protocol of a physical activity study which tested the effects of an intervention on health outcomes and the well-being of people living with a dementia in residential accommodation. The protocol was generated from a systematic review of physical activity interventions with people living with a dementia.

Method: The systematic review was used to develop an evidence based protocol for a physical activity intervention undertaken with people living with a dementia in residential accommodation by a physiotherapy doctoral candidate in South Australia.

Findings: The physical activity protocol consisted of a range of physical mobility activities (strength, balance, endurance and flexibility) for two groups of participants: (i) physically active individuals and (ii) individuals participating in sitting activities. This ensured most people with a dementia were eligible to participate in the study. The effectiveness of the protocol was tested through a randomised controlled trial. The health outcome measures were a range of mobility measures and well-being was measured using the Cohen-Mansfield Agitation Inventory.

Conclusion: An evidence-based physical activity protocol for people living with a dementia in residential accommodation was implemented and tested using a randomised controlled trial. The findings identified the strength, balance, endurance and flexibility physical activities which are specifically effective for: (i) physically activity-individuals and (ii) individuals participating in sitting activities. The findings are being implemented by the doctoral candidate as she continues her work as a physiotherapist with people living with a dementia in residential accommodation.

P10.5. Social stimulation and dementia: does it have an impact on social interactions of people with dementia living in nursing homes?

MABIRE Jean-Bernard, GAY Marie-Claire, VRIGNAUD Pierre, CARITTE Catherine, VERNOOIJ-DASSEN Myra

Introduction: People with dementia living in nursing home do interact with others. Very few studies focused on the impact of psychosocial interventions on social interactions. The objective of this study is to assess the direct impact of one social stimulation session on social interactions of people with dementia.

Methods: 60 volunteers with moderate dementia living in a French nursing home were paired in groups of six residents. 36 residents were assigned to participate at one social stimulation session and 24 residents to a control group. Social stimulation consists in one 40-minutes session including participants’ presentation, reminder of the four seasons, social interactions between residents and with caregivers. Participants in the control group sat together at a table with newspapers on the table without direct stimulation. Comparisons before-after the session between the groups were analysed in a statistic way. Comparisons before-after the session between the groups were analysed in a statistic way.

Results: The observation tool has good stability of measure: each element of temporo-spatial orientation and 4 exercises about the four seasons. Social behaviours were videotaped and analysed with a validated grid of observation, the Social Behaviours Residents Index (SOBRI) (Mabire et al, submitted) according two components: social interactions between residents and without direct stimulation. Comparisons before-after the session showed that 23 residents out of 24 residents increased significantly in social interactions between residents against 11 (45.8%) for the control group.
Conclusion: social stimulation seems to promote social interactions with caregivers and between residents. These results are encouraging. Further studies are needed to confirm these trends in a largest sample and in a long-term social stimulation.

P11.1. The power of theatre – creating bespoke performances for an audience with dementia

SCHAMBERGER Magdalena

Scottish charity HeArts & Minds researched and developed the Elderflowers programme for people living with dementia with encouragement from the Dementia Services Development Centre in 2001. Elderflowers uses European style theatre clowning to connect with people in the mid to advanced stages of dementia, in healthcare locations across Scotland. It uses a unique clown family concept to positively transform healthcare environments by creating meaningful and lasting relationships with participants, family members and healthcare staff. Elderflowers uses the performing arts to encourage communication, interaction and laughter and create links with participants who are often otherwise considered as ‘hard to reach’. Their trade-mark is the red nose, widely considered the smallest mask in the world. It connects the performers with their own vulnerability, openness and playfulness and acts as a visual focus, a point of recognition and signifier for the participants. It facilitates being ‘in the moment’ and sharing their vulnerability and humanity.

As a recent Paul Hamlyn Breakthrough Fund recipient, Artistic Director, Magdalena Schamberger is currently in the process of researching and developing bespoke performances for an audience of people living with dementia and their carers, to invite them into theatre and community settings and to include and engage them in stimulating cultural activity. In addition she is developing an experiential training programme for artists from all art forms, to increase engagement with this particular audience group. Most recently Magdalena has adapted an existing version of “A Clean Sweep” by Plutôt la Vie, which was performed at Festival Theatre Edinburgh in February 2015, in what may have been Scotland’s first professional dementia friendly performance. In ‘The power of theatre – creating bespoke performances for an audience with dementia’, Magdalena will share her research journey and her attempt at creating a methodology to encourage and enable other artists across Europe to follow suit.

P11.2. “A Place to Sit”

BLACK Kevin, NELSON Deirdre

“A Place to Sit” came from a partnership between Alzheimer Scotland and Luminarte, Scotland’s Creative Ageing Festival. Deirdre Nelson (artist) was commissioned to work with people in Glasgow with a diagnosis of dementia, over a period of ten weeks, to create something which would go on display, as an example to the public of what people with dementia CAN do, CAN create and CAN contribute. Two of Alzheimer Scotland’s Glasgow services got involved and a total of 27 people with dementia participated throughout the project. It started with conversation, getting to know people, and then, introducing images. Participants chose images they liked, felt drawn to or that meant something to them. Taking these images as a starting point participants were then offered different ways to get involved including drawing, painting, tracing, colouring, making collages and making decisions.

Over the course of the project the participants created wonderful, vibrant images of their own. Their enjoyment was clear to see and hear with those who usually didn’t say much sharing stories and those who don’t always participate getting involved and making decisions. They decided to use their designs for tablemats and coasters to use within both services and so the final designs were scanned into the computer and sent to an online company to turn them into tablemats and coasters.

The positive outcomes for the participants continued with increased self-esteem and self-worth from seeing their work turned into a professional, useful product and knowing that others wanted to buy their designs. The original tablemats and coasters are now back with both services, being used every day with the designs sparking conversations and memories for all.

This presentation will show that the processes were simple, the involvement was varied and the outcomes were positive and powerful. It will also highlight how this project is now a part of Alzheimer Scotland’s “Spotlight” series, taking what was learned; the techniques to encourage involvement, the positive outcomes, and the simplicity of it, and sharing that with staff to enable and encourage them to embrace art to enrich the lives of people living with dementia.

P11.3. Memory, Aging & Expressive Arts: Fostering meaningful art experiences for persons with dementia

MONDRO Anne

Coming from the art and health perspective, the presentation will address the use of creativity to foster meaningful intergenerational relationships for persons with dementia. Using University of Michigan (U-M) Professor Anne Mondro’s course, Memory, Aging & Expressive Arts as a model, the presentation will focus on designing creative experiences to invite discussion and an exchange of knowledge through imagination, experimentation, and discovery. Uniquely engaging U-M academic units and the U-M Health System, Memory, Aging & Expressive Arts focuses on developing students’ sensitivity and understanding towards those experiencing changes in memory or thinking through shared art experiences. Students from across campus meet with specialists in neurology, public health, social work, and the arts to learn about the scientific basis of memory and dementia, the societal basis of dementia, and institutional projects to support persons with dementia.

Partnering with the U-M Geriatrics Center Silver Club Mild Memory Loss Programs, students are paired with persons with dementia to explore and enjoy their creativity through visual art, music, dance, and writing. Through these sessions, students and persons with dementia...
explore the potential of the arts to serve as an outlet for expression. The speaker will key cover course objectives and learning paths designed to nurture compassion through creative experiences including overcoming pre-determined attitudes about aging and dementia, exploring the benefits of creativity, and utilizing the expressive arts to improve one’s quality of life. Through creative project vignettes, the speaker will address the necessary training for students to work with persons with dementia and emphasize how to design and facilitate reciprocal creative experiences. The vignettes will also capture reflections by students and persons with dementia to illustrate how creativity is a tool for connecting to others.

P11.4. Innovative gallery project connecting art, community and people with dementia

SERRANI Virginia, DARVO Gianluca

While Alzheimer and other dementia diseases are rapidly growing all over the world, we should find some way to pull care facilities, people and Alzheimer disease itself away from the corner, opening buildings and minds. Create specific semipublic spaces into dementia facilities to host social functions and activities can be a vehicle to improve active involvement, inclusion, and integration of patients, relatives, stakeholders, and the whole society. For this purpose, we have chosen to place an art gallery in the wandering path. We have chosen art as a vehicle to connect what and who is inside and outside facilities because art is mainly perceived through emotive channels, and it is not always necessary to use the cognitive sphere. Art reaches every people, even if in different ways, regardless their physical or cognitive frailties. The permanent art gallery we created in the wandering path of the Daily Centre for Alzheimer disease in Fano (Italy) is called “Margherita” and is open both to daily center guests and to external visitors and citizens. The aim of the project was to create a strong element of integration among the centre, its users, and the city. Hosting art exhibitions in a permanent art gallery, the wandering path has become a semipublic space, open to accommodate in rotation artworks from professional painters and sculptors from the territory. Now it is a key support not only for wandering, but also for occupational, physical and psycho-social activities.

This project is an important resource from two points of view: artists and community can use some spaces in the Alzheimer Centre and, on the other side, people affected from dementia benefit from the presence of artworks and visitors in the facility, with a global improvement of culture and social interaction.

P11.5. Ageing and dementia in children’s literature

BILBAN Tina

The presentation of specific topics in children’s literature is a good indicator of how society understands and treats them. We analysed how biological ageing is presented in children’s literature and integrated into the broader social picture of ageing. We were specifically interested in the presentation of age related diseases such as dementia. We analysed picture-books published in Slovenia and the UK since 1990. A search of UK’s and Slovenian biggest archives of children’s books resulted in 104 British and 73 Slovenian picture-books dealing with either older people, ageing or age related diseases. We found that less than 10% of all picture books from our selection included elements of biological ageing. This percentage was similar in Slovenian and British books; however there were more high quality presentations of biological ageing in the British sample of books. In children’s books older people are rarely presented as ill: two British picture-books featured older people that suffered from dementia and one discussed respiratory diseases, while in the Slovenian set one book featured a granddad with the flu and another grandparents with confusing unnameable diseases, including some symptoms of dementia. Death is discussed mostly on the metaphorical level and only four picture-books in total touched upon the process of dying. We reached the conclusions that rare inclusion of biological elements in children’s literature indicates that society is anxious of science as well as of diseases and death and considers this topics inappropriate for children. However, rare exceptions among the analysed books that communicated ageing and diseases such as dementia in all their complexity (e.g. Reeve Lindbergh’s My little grandmother often forgets) succeed to address their target public by retaining their emotional impact and adding to their vibrancy.

P12.1. Towards a restraint free dementia care – a national initiative

HOFFMAN Wilhelmina, NORDBERG Gunilla

Since the 80’s there has been an ongoing discussion in Sweden regarding restraints in dementia care, and it has been the subject of numerous investigations. Even if the intent is good, the use of restraints within dementia care is not consistent with the Swedish Constitution. Is dementia care without restraint really possible? Some argue that this is impossible, whilst other claim that a restraint free care is possible by constantly revaluate and develop alternative working methods. A restrain free care is about preventing threatening situations and behavioural and psychological symptoms of dementia (BPSSD) that can create disturbance. Person-centered care is the key to avoid difficult situations and develop strategies to approach if these troublesome situations occur. This prevents the risk of thinking that restraints are the “only solution”. The Swedish Dementia Centre (SDC) received 2013 a commission from the Swedish government to create an educational package regarding
how to work towards a restraint free care. SDC has developed the package, under the name “Vision Zero”, with the help and support of many experts and knowledgeable persons around the country. The package consists of web based educations, one for leaders and one for care workers, a handbook on the web and in paper format for people working within the area. In addition a pamphlet for family carers and two applications for smartphones and tablets. Our hope is that this package will lead to a dementia care free from restrain.

The knowledgebase of dementia is under intense development at the same time as the care of persons with dementia face both opportunities and challenges.

SDC, established 2008, is a non-profit foundation and the Swedish national centre for excellence in dementia care. SDC actively promotes future development in care of persons with dementia – towards a more dementia friendly society.

P12.2. “If we can get through this week” – experiences of formal dementia home and community care in Ireland

Access to formal dementia care services varies widely within and across European countries. This paper presents Irish data from one study within the Access to Timely Formal Care (ActifCare) JPND-funded research project. The study explored the personal experiences, and perceived barriers or facilitators in accessing formal home- and community-based care services from the perspectives of people with dementia, informal caregivers, and healthcare professionals. An exploratory qualitative design with purposive sampling was used. Two focus groups were conducted with people with dementia already using, or having previously tried to access, formal care (n=8); three with informal caregivers of different ages and with different relationships to the person with dementia (n=16); and three with healthcare professionals from a variety of backgrounds (n=18). Discussions followed an agreed structure, were tape-recorded, transcribed, and analysed using inductive content analysis. Common themes emerged across the groups with regard to: (1) Understanding Care Needs, (2) Accessing Services and Service Availability, (3) Education and Awareness, (4) Capacity and Rights, (5) Best Practice, (6) The Impact of a Dementia Diagnosis and (7) The Impact of Caring. Conflicting views were evident between the wishes of people with dementia and their caregivers (formal and informal), and also amongst healthcare professionals regarding the most appropriate time for care. A theme of Problems Resulting from Poor Care also emerged from the healthcare professional groups. These findings are interpreted in the context of Irish health and social care structures and recommendations are made in light of the recent publication of the Irish National Dementia Strategy. The findings support the increasing body of evidence that highlights the very clear gaps that exist between the formal home- and community-based care that is available in Ireland, and the care advocated for by people with dementia, their informal caregivers, and health professionals alike.

P12.3. Project Palliare: equipping the qualified dementia workforce to support advanced dementia care and family caring

HVALIC Touzery Simona, TOLSON Debbie, MACRAE Rhoda, WAUGH Anna, HOLMEROVA Iva, HANSON E, WATCHMAN Karen

Demographic ageing is a worldwide process with the associated incidence of dementia expected to increase globally to over 80 million by 2040. In the early stages of dementia many people live independently but, as dementia advances, living well requires increased levels of support and care. People at the advanced stage of the illness are particularly vulnerable and their needs may be complicated by communication difficulty, pain and behaviour that carers find difficult to understand. This can result in poor quality of care as the person with dementia cannot communicate their needs and preferences. At the advanced stage, people with dementia and their family need to be supported by a qualified and confident care workforce, who is both evidence informed and supported to continually develop their practice. Workforce training, commitment to good quality continuing care and services for people living with dementia are WHO priorities. Education for care staff and partnership working with families is recognised at strategic and policy level across Europe. However, the reality is that research and training on advanced dementia is scarce. This highlights the importance, in the face of the rising incidence of dementia, for accessible education to support and manage care for people with advanced dementia, making use of modern technology, communication and networking to support learning in a virtual environment.

The purpose of the paper is to present an overview of a European Union Erasmus + funded two year project, ‘Palliare’ which began in September 2014. The project aims to collaboratively create a range of practice based and experiential online learning resources to support carers of people in the advanced stage of dementia. This will be facilitated through a virtual international Community of Practice – a learning environment where people with common interest come together to share and learn from each other, to meet pre-determined needs. This paper will focus on one of the activities from the Palliare project, the educational gap analysis of the qualified dementia workforce. This work will inform the development of the interprofessional learning modules. We will highlight the importance, and potential contribution, that this education can make in equipping the qualified dementia workforce to support advanced dementia care and family caring in the 21st century.

P12.5. Informing to improve: Exploring the views of people affected by dementia to develop better care pathways

KELLY Fiona, HEWARD Michelle, INNES Anthea

This paper reports on the Dementia Pathway Redesign project, funded by the National Health Service (NHS) England, Mental Health Dementia and Neurological Strategic Clinical Network. The aim of the
project was to develop a diagnosis and post-diagnostic dementia care pathway for people with dementia and their families in the South of England that met their needs and wishes in a more equitable way. To ascertain people’s current experiences of diagnosis and post-diagnostic support and identify gaps in services, seven focus groups were held throughout the region, representing its geographical (island, coastal and rural) and population size (city and small town) diversity. A total of 73 people took part: 27 people with dementia, 37 carers or family members and 9 representatives of local communities or support workers of existing groups. The age range of people with dementia was 59-87 years and the age range of carers/family members was 40-89 years. The focus groups were lively and participants were eager to share their experiences and pleased to be involved in research with the potential to improve their lives.

A thematic analysis of transcripts from focus groups revealed variability in the support and information participants received, which impacted on their experience of diagnosis and post-diagnostic support. Participants told positive stories of their experiences, while others told stories of uncertainty and distress. This paper reports findings from focus groups and recommendations for a future pathway informed by these findings. It also discusses how pressure from government targets to increase diagnosis rates in the region meant that the focus of the pathway shifted from local communities to care homes, with the consequence that the views of people with dementia and their family carers living in their own homes was sidelined in the development of the new pathway.

**P13.1. The stages of facilitating collaborative decision-making in dementia care networks**

**GROEN-VAN DE VEN Leontine, SMITS Carolien, SCHWARTZ Danielle, SPAN Marjke, JUKEMA Jan, EEFSTING Jan, ELWYN Glyn, VERNOOI-DASSEN Myrra**

**Introduction:** Person-centred care is the preferred way of caring for people with dementia. Shared decision-making is an important element of person centred care. Little is known about facilitating shared decision-making with multiple participants in the context of dementia. The current study aims to describe the stages of facilitating decision-making in care networks of people with dementia.

**Methods:** We interviewed people with dementia, their informal caregivers and professional caregivers (total of 117 interviews). We analysed the interview data using framework analysis. The theoretical model of collaborative deliberation, describing the interactions between multiple participants in decision-making, acted as our framework.

**Results:** Our analysis resulted in six stages of facilitating decision-making in dementia care networks: 1) engaging with the network, 2) eliciting the problem that needs addressing now, 3) developing alternative options, 4) learning about alternatives by deliberating and trying, 5) constructing preferences based on differing values, 6) integrating preferences while balancing conflicting interests and respecting adequate timing. Developing alternatives and learning about the pros and cons of alternatives are two-way processes. Through discussing the pros and cons, new alternatives can be developed.

**Conclusion:** Collaborative decision-making in dementia care networks is a process of deliberating and trying of participants with potentially conflicting values and interests. Problem elicitation is an important element in this process because of the different perspectives of the participants involved. Collaborative decision-making in dementia is aimed at finding ways of balancing conflicting values and interests between different participants.

**Practice implications:** Person-centred decisions in dementia are built on a network approach that acknowledges potential conflicting interests between participants. The stages of facilitating collaborative decision-making in care networks of people with dementia help in structuring the process of reaching shared decisions.

**P13.2. Creating a vision for change: Process evaluation of an appreciative inquiry approach to develop person-centred dementia care strategies in hospital wards**

**SCERRI Anthony, AGIUS Anne, CALEA Doris, INNES Anthea, SCERRI Charles**

**Background:** The quality of care of persons with dementia in hospital settings is far from optimal and can be very challenging. This has been partly attributed to the fact that hospital staff are untrained in person-centred dementia care. Staff training has been shown to positively influence staff and patient outcomes, although they may not empowered enough to translate what they have learned in practice.

**Objective:** The aim of this study was to introduce and evaluate the application of an organisational development approach known as appreciative inquiry during which the researchers worked collaboratively with the staff to develop person-centred dementia care strategies in two geriatric hospital wards.

**Methods:** An average of 35 staff members in two geriatric wards attended six workshops (repeated four times) during which they were guided to develop a number of possibility (vision) statements of their aspirations for a better ward environment, based on the positive care experiences of the past that were previously collected through appreciative interviews. Following the workshops, a questionnaire, was distributed to all participants in both wards to collect their reactions to the approach used.

**Findings:** Appreciative interviews were well received by the staff as they had the opportunity to reflect and share their skills with each other. All participants felt that they would recommend the workshops to their colleagues. Moreover, although the majority of the participants agreed that the themes discussed were not new to them, they felt that the workshops helped them to think about how to work in a more person-centred way and to develop action plans to improve the quality of care.

**Conclusion:** An appreciative inquiry approach has been positively accepted by hospital staff. Moreover it increased awareness and interdisciplinary collaboration to develop practical strategies for organisational change.
P13.3. Empowering care home staff to deliver dignified care to the person with advanced dementia

BROWN Margaret, MCWHINNIE Hazel, MCALISTER Janice, LOGAN Valerie, HERON Karen, BOOTH John, BAYLIS Maxine

This study used a participative approach to practice, learning and research in a project designed to explore innovative ways of enhancing dignity in eating and drinking for the person with advanced dementia living in a care home setting. The project team included family members, nurses, allied health professionals, support workers, catering staff and University researchers working together in a home for war veterans in Scotland.

An adequate nutritional intake is essential for physiological functioning and plays a key role in quality of life. Having no choice in what you eat and drink threatens dignity and personhood in a culture where choice of food and drink contributes to a sense of self.

The project involved six residents and their families. Staff and families attended an intensive education programme on eating and drinking in advanced dementia. Following this, for an intervention period of 12 weeks, a sensory framework was used to explore and record ways of improving the dining experience for the person with advanced dementia.

The residents maintained their nutritional status and their eating difficulties decreased. Families and staff reported improved understanding of the challenges faced by the residents and developed more open communication with one other. Staff report increased understanding of the challenges faced by the residents and developed more open communication with one other.

They also indicate a wish to be involved in more research projects. Learning throughout the project has given staff a toolbox of interventions that they are beginning to use to deliver person centred care. This study has shown that empowering the nurse within a care home environment helps facilitate mutually beneficial partnerships between staff, residents and families. This participative approach may lead to care staff that are ‘research ready’.

P13.4. Dimensions of quality of life from the perspective of people with dementia – a meta-synthesis

DICHTER Martin Nikolaus, PALM Rebecca, HALEK Margareta, BARTHOLOMEYCIK Sabine, MEYER Gabriele

Background: Despite missing theoretical clarity, quality of life (Qol) has become a major concept as outcome in intervention studies in dementia research. There is no generally accepted definition of Qol for people with dementia. Lawton’s model (1991), which includes subjective and objective components, is widely used as framework for the development of Qol measurements and interventions, although it is not well empirically funded.

Method: The meta-synthesis (PROSPERO 2013: CRD 42013005014) followed four methodological steps: (a) comprehensive database search without time limit and subsequent forward and backward citation tracking, (b) data extraction using the template form of the Qualitative Assessment Review Instrument, (c) quality appraisal using formal criteria from the Critical Appraisal Skills Programme, (d) synthesis of findings based on principles and procedures of grounded theory. In particular, the constant comparative method guides the coding, identification of categories and synthesis. Two independent reviewers carried out all four methodological steps.

Results: Through comprehensive search and removal of duplicates 2,716 eligible references were identified. Application of inclusion criteria revealed eleven studies (from seven countries, published between 1995 and 2011) for inclusion. The papers covered reports on the perspectives of 373 people with dementia in all stages of dementia on their Qol. A total of 14 different Qol domains were identified: family, social contact and relationships, self-determination and freedom, living environment, positive emotions, negative emotions, privacy, security, self-esteem, health, spirituality, care relationship, pleasant activities and future prospects. Presently, the relationship between the domains is analyzed aimed to develop the final Qol-model. The results will be available in June 2015.

Conclusions: Our meta-synthesis will contribute to the theoretical development of the concept of Qol of people with dementia. The resulting dementia-specific model will provide a framework for the development, adaption and validation of dementia-specific Qol measurements and development of psychosocial interventions.

P13.5. Promoting continence for people living with dementia and long term conditions

DENNIS Jacqueline, EDWARDS Heather, NOONE Archie

The “Promoting Continence resource for People Living with Dementia and Long Term Conditions” is an example of partnership working involving people living with dementia and their families and carers with staff from across the health and social care sector. The project was led by the Care Inspectorate which is Scotland’s independent scrutiny and improvement body for care services in Scotland.

The resource has been designed as an easy read guide with an accompanying DVD to support the key messages that can be used by people to manage their own continence as well as by carers both informal and formal in a wide variety of settings. The resource is based on best practice and current research and is person centred in its approach, advocating thorough assessment and using strategies to maintain independence and dignity.

The stigma and assumptions that are made in relation to people with dementia and older people in general mean that incontinence is often accepted as an inevitable aspect of ageing. This resource aims to highlight the fundamental and essential care and support that is required to give people the opportunity to remain continent.

There are currently 88,000 people diagnosed in Scotland with dementia, for many the expectation that they will remain continent especially when they move into a residential care setting is alarming low. There is growing evidence linking incontinence with the rate of falls mobility issues, increased risk of urinary tract infections as well as the impact on quality of life.
The presenters would like to demonstrate how involving people with dementia and their carers in the development of this resource has strongly influenced the key messages and produced a resource that combines current best practice with what matters most to people who are using care and support services.

**P14.1. Burden of behavioral and psychiatric symptoms in people screened positive for dementia in primary care – results of the DelPHi-study**

**THYRIAN Jochen René, EICHLER Tilly, WUCHERER Diana, DREIER Adina, MICHALOWSKY Bernhard, KILIMANN Ingo, TEIPEL Stefan, HOFFMANN Wolfgang**

**Background:** There is limited knowledge about the range and effects of neuropsychiatric symptoms shown by persons with dementia (PWD) living in the community and their related caregiver burden.

**Objective:** (a) to examine neuropsychiatric symptoms in PWD in primary care in regard to frequency, severity and burden to caregiver, (b) compare PWD with and without symptoms in regard to sociodemographics, care- and disease-related variables, (c) identify variables associated with symptoms.

**Methods:** Assessment of the Neuropsychiatric Interview (NPI), sociodemographics and disease –related variables in a general physician-based epidemiological cohort of n=248 people screened positive for dementia above 70, living at home and their caregivers.

**Results:** In preliminary analyses neuropsychiatric symptoms were frequent in PWD. Prevalences of dysphoria/ depression, apathy and agitation/ aggression were each more than 30%. The severity of neuropsychiatric symptoms in people screened positive for dementia in primary care is moderate with a mean NPI score of m =11.91, (SD=16.0). Overall, caregiver distress is low, indicated by a total distress score of m=5.94 (SD=7.2, range 0-39). Common or frequent symptoms are not necessarily the most distressing symptoms.

**Conclusions:** Neuropsychiatric symptoms are common in people screened positive for dementia in primary care. While frequency, severity and perceived distress might be low in the total sample, we identified the dimensions delusions, aggression, anxiety, disinhibition and depression to be perceived “severely” to “extremely” distressing in more than 30% of the caregivers affected. The association between ADL and symptoms needs further attention in care.

**P14.2. Importance of behavioral symptoms on caregivers needs: The impact on community services**

**SETZER Manuela, SCHALLER Sandra, MARINOVA-SCHMIDT Velslava, WART Ina, LUTTENBERGER Katharina, CRAESSEL Elmar, MALER Juan Manuel, HOESL Katharina, MASSICOT Gudrun, POPP Susanne, SIEGL Carlo, ANHERT Andreas, KORNHUBER Johannes, KOLOMINSKY-RABAS Peter**

**Background:** Neuropsychological behavioral problems often occur in persons with dementia (PWD) and play a vital role for informal caregivers involved in their care.

**Methods:** Data of the Erlanger Dementia Registry (2012-2014) has been analyzed (N=91). The data was collected with standardized instruments (Charlson Index, NPI, CNA-D) during face-to-face interviews with persons with dementia and their informal caregivers at baseline (T0).

**Results:** 63% of the caregivers reported a tendency of perceived burden, caused by explicitly depressive symptoms of the PwD. 39% of the caregivers reported a personal affliction caused by PwD suffering from a loss of interest and mood swings. The caregivers’ perceived experiences of perceived burden, as a result of the neuropsychological behavioral problems of PwD, are also reflected in their statements concerning support for caregivers. In this context, a strong need for support could be identified in the area of emotional distress, in contrast to areas of organization or information. In the case of emotional distress, 36% of caregivers admitted being overwhelmed by the situation and 34% reported suffering from depressive symptoms. The informal caregivers asked explicitly for more psychological therapy services, as well as guided and non-guided support groups.

**Conclusion:** These results indicate that 1.) behavioral symptoms of dementia syndrome need to be taken into account at the time of diagnosis, and 2.) for informal caregivers, these symptoms have a strong influence on the perception of personal distress and 3.) there exists a vocalized need for support-services for families caring for PwD. Such services are explicitly desired by caregivers in the context of coping with the caregiving situation.

**P14.3. Depression, anxiety and quality of life in relatives of individuals with dementia in Malta**

**SCERRI Charles, MUSCAT Marthese**

In Malta, most of the care for individuals with dementia is delivered at home by members of the family. Due to the nature of dementia, in which progression leads to increased dependency, the delivery of around the clock informal care leads to caregiver physical and psychological burnout. Indeed, various studies suggest that the majority of family caregivers would develop psychological and behavioural problems including anxiety and depression which undermine their quality of life.

The main objective of this study was to comprehensively identify and determine the levels of anxiety and depression in family caregivers of individuals with dementia and how this impacts their quality of life. The results have shown that there is a strong positive correlation between anxiety and depression and that both significantly affected the four domains of the WHO-QOL-BREF instrument. Furthermore, the most important parameter that had an effect on depression was the loss in activities of daily living experienced by the relative with dementia. The presence of depression in the relative led to a significant increase in the level of burden as measured by the Zarit Caregiver Burden Scale.

The data obtained continues to add on the need of developing services that address the psychological and behavioural needs of relatives caring for individuals with dementia.
P14.4. Sensory gardens in dementia care: An evidence-based translation into practice

PROLO Paolo, SAREDO-PARODI Antonio, SASSI Enrico

Aims and objectives: To translate into an actual project the results of a systematic review on the benefits associated with the use of sensory gardens in dementia care.

Background: Sensory gardens are increasingly used in dementia care, yet their benefits are uncertain as a pure therapeutic tool, although they might improve personal feelings and quality of life.

Design: A systematic review with descriptive analysis of selected empirical studies was conceived as a base for a novel project of sensory garden in an elder daytime health care center in Balerna, Switzerland.

Methods: We performed systematic searches on MEDLINE, ISI Web of Science, Embase. Search terms were the free-text concepts 'healing garden', 'horticultural therapy', 'restorative garden', 'sensory garden' and 'wander garden' which were combined with dementia and Alzheimer's.

Results: Eighteen studies were included with included participants ranging from eight to 129 participants. Research designs were case studies (n = 3), survey (n = 2), intervention studies with pretest/post-test design (n = 11) and randomized controlled studies (n = 2). Of these studies, eight examined the benefits of sensory gardens, eight examined horticultural therapy or therapeutic horticulture and two examined the use of plants indoors. Results are mutually supportive with some contradictory findings. Nighttime sleep patterns, aggressiveness and anxiety seem to improve.

Conclusions: We designed an open but well delimited and protected space, appearing as an accessible, simple and normal garden to counterbalance aggressiveness and anxiety. The garden allows to stroll safely and to satisfy one's wandering on an elliptical circuit around the garden. The garden demonstrates good results in terms of quality of life and also in behavioural problems. An improvement has also been measured in sense of competence, quality of life, mood and perception of assistance for caregivers.

P15.1. Mobile dementia counselling: an instrument to support informal carers in rural areas in Germany

HAMPEL Sarah, REICHERT Monika, REUTER Verena

Studies show that comprehensive and accessible counselling for people with dementia and their informal carers can improve the informal care setting in many ways. For example, a need-oriented and early use of counselling is fundamental for using professional care services. However, many informal carers do not use counselling due to various reasons such as an information deficit and a lack of (regional) accessibility of counselling.

The Rhine-Erft district, a rural area in Germany, improved its network of dementia care services by establishing a mobile gerontopsychiatric counselling with special focus on dementia. A specially equipped “counselling bus” offers free counselling at several public places in towns and villages of the district at least once a month. The counselling-team consists of two persons: one is a qualified full-time staff member from one of the co-operation partners (welfare associations or local social services) and the other is a qualified honorary consultant. The main objectives of the counselling service are to give informal carers an individual and neutral overview about local care services and to raise awareness for people with dementia. Using a multi-method approach, the concept “mobile dementia counselling” was evaluated with the aim to determine how mobile dementia counselling has to be designed and implemented to meet the needs of informal carers.

The results show first, that mobile dementia counselling is a low-threshold and successful way to reach informal carers and to inform them about different aspects of dementia care. Second, it contributes to moderate dementia living at home and their respective caregivers. The treatment consist in ten sessions of occupational therapy at home. The main outcome measures are Canadian Occupational Performance Measure (COMP) and Sense of Competence Questionnaire (SCQ). Other outcome measures are: Mini-Mental State Examination (MMSE); Quality of life-AD Measure (QOL-AD); Neuropsychiatric Inventory (UCLA-NPI); Disability Assessment for Dementia (DAD); ZARIT Burden Assessment (ZARIT); Center for Epidemiologic Studies Depression Scale (CES-D); SF-12 Health Survey (SF-12); General Health Questionnaire (GHQ-12); Geriatric Depression Scale-30 (GDS-30). Participants were evaluated at baseline and at the end of treatment.
P15.2. Caregivers’ of people with dementia perceptions of resilience and the factors that strengthen resilience

MURPHY Kathy, CASEY Dympna

Background: Approximately 26,104 people with dementia are living in the community in Ireland being cared for by family and friends. Carers report a lack of support, information and skills. Many therefore experience high carer burden, are at risk of mental and physical illness, and become socially isolated. These problems can result in being placed in residential care prematurely which has significant economic and health costs. However little is known about carers perceptions of resilience and the factors that strengthen their resilience.

Aim: This study explores carer’s perceptions of resilience and the factors that facilitated or hindered their resilience when caring for people with dementia.

Methods: A descriptive qualitative study was conducted based on the work of Thorne (2004). Semi structured interviews with a purposive sample of twenty eight (n=28) persons with mild dementia were undertaken. In particular the interviews focused on careers resilience in caring for persons with dementia, how their capacity for resilience could be enhanced to assist and support them to continue caring for the person with dementia in their own home for as long as possible. All interviews were tape recorded and transcribed verbatim. Transcripts were analyzed for themes and Windle (2012) resilience framework was used to guide the analysis. The criteria identified by Lincoln and Cuba (1985) were used to ensure and maintain rigor.

Findings: Findings indicate that internal and external factors influenced participant’s resilience. These included self-esteem, coping style, knowledge of dementia, supports and engagement in pleasant activities, maintaining social networks, connection to, and learning from, other carers, humour and time for self. This study concludes that resilience is important to the sustainability of caring for people with dementia and resilience can be strengthened providing appropriate supports are in place.

P15.4. Family caregiving in young onset dementia in Flanders (Belgium): an exploration of the needs of caregivers

SPRUYTTE Nele, Van VRACEM Marelke, MORTIER Philippe, BRUFFAERTS Ronny, VANDENBULCZE Mathieu, Van AUDENHOVE Chantal

The department of geriatric psychiatry of the university hospital of Leuven and LUCAS KU Leuven collaboratively conducted an explorative study on the needs of family caregivers of persons with young onset dementia in Flanders (Belgium).

We recruited 23 family caregivers of persons with early onset dementia: 21 spouses, 1 parent and 1 sibling. A short structured questionnaire and HIClass-grid were combined with a semi-structured interview with the participants. Data were analysed using thematic content analysis.

Experiences of receiving the diagnosis of dementia confirm earlier research that stipulates the difficult and often long process of diagnosing dementia. We found that the general practitioner may have an important role in facilitating or hampering this process. Family caregivers stress the feelings of loneliness in the search for support for the person with dementia. However, they are positive about the current care initiatives (e.g. day care). The needs of family caregivers are diverse: from information related to the disease, over practical help, emotional support for themselves and their children, to individualized advice on meaningful day-to-day activities. A lot of caregivers ask for case management as a continuous form of personalized support.

Based on these results, we provide recommendations to improve support for families confronted with early-onset dementia.

P15.5. Factors associated with satisfaction in informal caregivers of dementia patients

JENSEN Anders Møller, DE LABRA Carmen, BUJÁN Ana, NÚÑEZ-NAVEIRA Laura, MILLÁN-CALENTI José Carlos, MOJS Ewa, SAMBORSKI Wlodzimierz, GREGERSEN Rikke

Introduction: As life expectancy of people increases, the prevalence of different pathologies and age-related syndromes also rises. In this sense, the prevalence of dementia along with the demands and concerns of the caregivers of dementia patients have incremented considerably. The research on this field has mainly dealt with the negative aspects of caregiving, specifically with caregiver burden and depression. However, less attention has been paid to the positive aspects of caregiving.

Objective: The aim of this study is to determine some of the factors that could predict the phenomenon of caregiving satisfaction in informal caregivers of people with dementia.

Method: 101 family caregivers of patients diagnosed as having dementia participated in this cross-sectional study. A stress process model was used to study caregiver’s satisfaction in relation to the caregiver’s background and context (caregiver age, caregiver gender, level of education, marital status, type of relationship with the care recipient, employment status, and duration of caregiving), stress-related factors (care recipient dementia severity, frequency of care, subjective burden, likelihood of changing work shift, leave work to take care of the relative, and caregiving competence), and mediators (support from the general practitioner, dementia supervisor, relatives and friends, home services, respite care services, self-help groups perceived social support, and satisfaction with social support).

Results: Multiple regression analyses revealed that having a consanguinity relationship with the care recipient, suffering from lower levels of subjective burden, and caring individuals with severe...
cognitive impairment are the most significant predictors of higher caregiving satisfaction.

**Conclusions:** Interventions should be addressed to caregivers without having a consanguinity relationship and with high levels of subjective burden, and to those managing care recipients with mild or moderate stages of dementia. These findings suggest that the interventions should be focused on the enhancement of the caregiving satisfaction by increasing the understanding of the illness.

**P16.1. Dementia friendly communities across Europe – findings from a mapping survey**

**WILLIAMSON Toby, HARE Philly**

Dementia-friendly communities are a concept that has gained widespread recognition and activity across many European countries. Policies, projects, and initiatives aimed at making municipalities, cities, towns and villages more dementia aware, supportive, and inclusive of people with dementia have grown considerably in number over the last few years. This presentation will report the findings from a Europe-wide mapping survey of dementia-friendly communities undertaken by the UK’s Mental Health Foundation in 2014, and funded by the European Foundations’ Initiative on Dementia (EFID) which includes the Joseph Rowntree Foundation. The survey gathered information from a wide range of organisations working in this field, about their work, both conceptual and practical factors that were considered to be important in the development of dementia friendly communities, and examples of notable practice.

There were 194 respondents to the survey covering 19 different countries. A number of common factors and themes emerged from the survey as well as some differences between countries. The presentation will present the findings from the survey together with examples of notable practice and will be of great interest to anyone involved in the development of dementia friendly communities in Europe.

**P16.2. Creating a dementia friendly workplace – a practical guide for employers**

**McNAMARA George**

As the workforce ages and the number of people retiring at a later age increases, the number of people living with dementia while they are in work is set to rise. This has implications for employers, who are beginning to recognise that dementia is becoming an increasingly big issue for their organisation and their staff.

A dementia diagnosis doesn’t necessarily mean a person can no longer do their job. However, dementia is a progressive condition and over time it will increasingly impair a person’s ability to work. As this happens, they may need support to help them remain at work. Eventually, they may need information from their employer about leaving work. This might include discussing retirement options and access to financial advice.

Similarly, support will be needed for those who decide they no longer want to work following a diagnosis of dementia. Finally, some employers will specifically wish to recruit and employ people who have the lived experience of dementia, for example as peer support workers. This practical guide is for all UK employers – across all sectors and of all sizes – to help them provide this type of support for the people with dementia and carers they employ.

It includes information about dementia, its symptoms and common issues faced by people with dementia:

- information about your legal responsibilities in relation to the protection of people with dementia from discrimination
- ideas to help you develop awareness of dementia in your workplace
- step-by-step tips to help you support a member of staff who is affected by dementia at different stages of their dementia journey, covering a number of common workplace scenarios
- information and guidance on making reasonable adjustments to ensure people with dementia are not disadvantaged in the workplace
- a list of organisations that can give further advice and support to you as a manager and to employees who either have dementia or care for someone with the illness.

**P16.3. The impact of living with missing incidents: How the experience and fear of missing incidents affects people with dementia and those who care for them**

**HOLMES Lucy, SHALEV-GREENE Karen, CLARKE Charlotte, PAKES Francis.**

When someone with dementia goes missing, whether they have become disorientated on a regular route, left home without telling anybody, or set out without a planned destination, the impact on them and the people who care for them can be significant and long lasting. Based on in-depth interviews with family carers, this exploratory study has aimed to explore the impact of ‘missing’, and the fear of missing incidents, on people caring for someone with dementia living in the community. Using a conceptual framework incorporating the notions of ‘freedom’ and ‘total institutions’, the study examines the ways in which risk-mitigating behaviours have an impact on the freedom of carers and people living with dementia.

UK police forces responded to 306,000 missing person reports in 2012-13; around five per cent concerned people aged over 60 years. When someone with dementia is reported missing, it is likely that they will receive a higher risk assessment level than many other missing people. Biehal et al (2003) state that those with dementia who go missing are usually found within a few days but the impact on the police is nonetheless significant; estimates of the cost of a single missing person incident range between £600 and £2,500, depending on the risk level and duration of the incident (Shalev-Greene and Pakes 2013). This paper will describe the study’s findings about a range of subjects, including carers’ knowledge about missing; the impact of coping
P16.4  Living in the community: travelling with dementia

McADAM Nancy, Scottish Dementia Working Group

**Background:** The Scottish Dementia Working Group (SDWG) is a national campaigning group, run by people with dementia and is the independent voice of people with dementia within Alzheimer Scotland. The Working Group campaigns to improve services for people with dementia and to improve attitudes towards people with dementia.

**Aims:** The group identified travel, particularly when using public transport, as an issue that people with dementia can find challenging. They wanted to find safe ways to travel and be able to share these with others across Scotland and to raise awareness of their issues amongst transport staff.

This presentation describes the process of how the group members set out to resolve these issues.

**Method/Participants:** In 2013, six members of the group came together to form a “Transport Sub-group.” The group meets 6 times a year, and these meetings have been held at different venues and involved members trying out various modes of travel to help fully understand the challenges faced.

They decided that the best way of tackling these issues was by producing a booklet entitled ‘Travelling with Dementia’.

The group has worked with major transport agencies and has provided training and advice for agency staff to raise awareness about the issues surrounding travelling well with dementia.

**Findings/Desired Outcomes/Conclusions:** The “Travelling Well with Dementia” (2014) publication includes useful hints and tips for travelling. It includes practical measures to make the journey safer and minimise stress, and signposts readers to services and organisations that can provide further assistance and/or resources.

Providing support and advice for people with dementia, and increasing awareness within the transport sector, and within the general public, has empowered many people with dementia to get out and about as independently as possible thus increasing self-esteem and confidence and strengthening their own personal capacity and resilience.

P16.5  Fire risks and safety strategies in the homes of people affected by dementia.

HEWARD Michelle, KELLY Fiona

Impairment, disability and dementia are substantial factors in increasing the risk of injury or death from fire in the home. Given the predicted rise in the numbers of people affected by dementia internationally, it can be assumed that the risk of fires in the homes of people with dementia will also increase unless dementia-specific fire prevention guidance is developed. The aim of the Fire Safety Innovations for People Affected by Dementia project is threefold: 1) to develop guidance that can be used internationally to help people affected by memory problems or dementia to be safer in their homes, 2) enhance the quality of life of people affected by dementia by enabling people to live independently in their own homes for longer, 3) to create a training package that will ensure Fire and Rescue staff and volunteers, and other practitioners who visit people in their own homes, are better equipped to work with people affected by dementia to ensure they are as safe as possible from fire risk.

This paper reports on the findings of focus groups that explored fire risks and safety strategies in the homes of people affected by memory problems and dementia. Focus groups were conducted with people with dementia and carers, Fire and Rescue Service staff and volunteers, and other practitioners who visit people in their own homes. This project is the first in the UK to develop a critical understanding of fire risk and prevention strategies in the homes of people with dementia and to create a much-needed approach to reducing fire incidents, injuries and deaths.

P17.1  Alzheimer’s society’s information programme for south Asian families

CAMPBELL Zoe, SMITH Kathryn

The number of people from minority ethnic groups living with dementia in the UK is rising steeply, yet awareness levels and diagnosis rates remain worryingly low. It is estimated there are almost 25,000 people with dementia from BAME (Black, Asian and minority ethnic) communities in England and Wales with this number is expected to grow to 172,000 by 2051. Unfortunately the services available tend not to reflect this and are mainly delivered in English with activities bearing little relevance to cultural elements such as language, faith or family structure.

Alzheimer’s Society (UK) has been developing a number of tailored dementia services for BAME communities which aim to break down some of the barriers which can stop them from accessing services. The Information Programme for South Asian Families (IPSAF) has been funded by Lloyds Banking Group and comprises of a series four of face-to-face sessions and an educational DVD for participants to take home and share with family members. The sessions are run by Alzheimer’s Society staff or volunteers, who undergo Cultural Competence training, alongside local faith and community representatives. The service is the first of its kind and has been co-designed with South Asian people and evaluated by the Bradford Dementia Group.

By March 2015, 20 programmes will have taken place in 18 locations across England. The project has been highly successful and will be available to all commissioners across England from April this year. To find out more about IPSAF visit www.alzheimers.org.uk/IPSAF.
P17.3. **Women and dementia: a marginalised majority**  
**RIDDICK Katy, SAVITCH Nada**

Dementia is an issue that disproportionately affects women. However, the facts about women and dementia and the experiences of women affected by dementia have been largely unrecognized by researchers, policy makers and practitioners.

We will present findings from two complementary projects which together address the issues around women and dementia in the UK. Alzheimer’s Research UK has collated the facts and figures about women and dementia. In the UK, dementia is the leading cause of death among all women. Not only are women more likely to have Alzheimer’s disease or another form of dementia, they are also more likely to be caregivers of those with dementia. Between 60 and 70% of all unpaid dementia carers are women. They are 2.5 times more likely than their male counterparts to provide intensive, on-duty care for someone 24-hours a day. Of those women, half found their caring responsibilities to be physically stressful, while even more, 62%, found the experience emotionally stressful.

The authors will discuss these and other findings from Alzheimer’s Research UK in the context of the real experiences of women collected as part of the Joseph Rowntree Foundation funded project – The Personal is Political: Women’s Experiences of Dementia. This project, run jointly by Innovations in Dementia and the Social Policy Research Unit at the University of York, worked in collaboration with women who have dementia, women who are unpaid caregivers for people with dementia and women who make up the majority of the dementia care workforce. Their words and photographs have been collated into a booklet that encapsulates the experiences of women and dementia. Together these resources will spark a debate in Europe about women and dementia. In the UK, dementia is the leading cause of death among all women. Not only are women more likely to have Alzheimer’s disease or another form of dementia, they are also more likely to be caregivers of those with dementia. Between 60 and 70% of all unpaid dementia carers are women. They are 2.5 times more likely than their male counterparts to provide intensive, on-duty care for someone 24-hours a day. Of those women, half found their caring responsibilities to be physically stressful, while even more, 62%, found the experience emotionally stressful.

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P18.1. What policy and practice change do we need regarding palliative care in dementia?

VAN DER STEEN Jenny T, GOVE Dianne, NAKANISHI Miharu, BRAZIL Kevin, RADBRUCH Lukas

Palliative care needs of people with dementia are different from palliative care needs of people with cancer or people with other chronic-progressive disease that do not necessarily involve cognitive impairment. The European Association for Palliative Care (EAPC) recently defined palliative care in dementia in terms of eleven domains. For each of the domains, recommendations for practice, policy and research provide guidance as to how to optimize care. However, from a policy and practice point of view, it is also important to understand how optimal palliative care in dementia differs from usual dementia care provided in different countries, how it should be implemented and possible barriers to its implementation. Therefore, we used the EAPC framework of domains defining palliative care in dementia to study literature to generate country-specific input for possible change. First, we evaluated the contents of national dementia strategies from fourteen countries, and second, we surveyed the perceptions of physicians providing end-of-life care for people with dementia in two countries with respect to barriers to implement palliative care in their countries.

Regarding the first study, we found that although palliative was not explicitly referred to in eight of the fourteen countries, a number of domains from the EAPC framework were well represented, including, for example, domains on continuity of care and family caregiving. However, only three countries addressed palliative care in a dedicated section, mainly referring to education and societal/ethical issues. All strategies lacked reference to the domains of prognostication/recognition of dying and to spiritual caregiving. Regarding the second study in 326 physicians, for most domains, general practitioners in Northern Ireland identified more barriers to implement palliative care in dementia than physicians specialized in care for older people in the Netherlands.

These findings may provide input to a discussion about integration of palliative care in dementia.

P18.2. Home hospice care for end stage dementia – a pilot project

CROFMAN Valeria, STERNBERG Shelly, KATZ Glynis

In Israel, 88% of the people with dementia live in their homes with home care, out of those, 31% of the individuals are in advanced stages. (Sternberg, Bartur, 2002). Evidence shows that advance stages of dementia are associated with complication such as chronic pain, recurrent infections, eating problems etc. These symptoms are associated with increased mortality rate and there is growing need for comfort care to alleviate symptoms and promote quality of life. However, at present in Israel, people with advance dementia are rarely recognized as being in terminal stages therefore they are not eligible to formal palliative care or hospice care. Three organizations, Maccabi health care service, Sabar Clinics- a private home care hospice, and EMDA the Alzheimer association of Israel, have partnered and initiated a time limited pilot project to offer 6 months hospice care for patients with advance dementia at home. This has not been done before in Israel in a focused and tailored manner. The aim of the pilot was to provide home palliative care to 20 families during a period of 6 months in order improve quality of care, learn and demonstrate the medical, emotional and spiritual benefits, as well as to make recommendation to stakeholders.

Families were screened, out of 33 Patients referred, 11 were found inappropriate and 22 were accepted, two dropped out, patients had a total of 50 hospitalization days prior. During the pilot there were 33 hospitalization avoided (aspirations, UTI, fever, etc.) Some of the challenges were identifying the accurate inclusion criteria for end of life in dementia. Recommendation includes ongoing training for caregivers, spiritual care, speech therapist evaluation and training on feeding, staff availability 24hrs/Wk, although only up to 15% home visits of the medical team outside regular working hours. Setting up equipment and medications at home in advance with training.

P18.3. Enhanced sensory day care: evaluation of a new model of day care for people living at home with advanced dementia

BROWN Margaret, WATCHMAN Karen, DALRYMPLE Amy, TOLSON Debbie, RICHARDS Naomi

There is a gap in the provision of day care services for people in the advanced stage of dementia who are living at home. As dementia progresses, the individual may not benefit from existing day care resource or service. A decision to stop attending day services may lead to difficulty for family carers, for whom replacement home care is unlikely to match the hours provided by the day care. Alzheimer Scotland Enhanced Sensory Day Care is a new model of day care attended twice weekly by people in an advanced stage of dementia. This is a sensory based approach that seeks to make connections with the person through the five senses: sight, smell, taste, sound and touch, delivered twice weekly over the twelve week pilot period. The pilot service was evaluated by the University of the West of Scotland with the aim of understanding the model in practice, and making recommendations for the development and continued delivery of this model for people in the advanced stage of dementia. The evaluation included pre and post quality of life measures as perceived by family carers, pre and post group interviews with staff and volunteers, individual interviews with family carers, and a pre and post self-efficacy scale with staff and volunteers to determine their confidence in supporting people at end of life.

Thematic analysis of data led to findings suggesting an increase in staff and volunteer understanding of, and skill in delivering, a sensory approach within a day care service for people in the advanced stage of dementia. Family carers perceived that their family member benefited identifying a desire to engage with activities at home upon returning from day care, increased communication and support for their own
wellbeing. The evaluation demonstrated the viability and potential of Alzheimer Scotland Enhanced Sensory Day Care as a model for the supportive care of people in the advanced stage of dementia.

**P18.4. Euthanasia in persons with severe dementia**

**CASTMANS Chris**

The number of people suffering from dementia will rise considerably in the years to come. This will have important implications for society. People suffering from dementia have to rely on relatives and professional caregivers when their disorder progresses. This provokes a feeling of being vulnerable in the people concerned. Some people want to determine for themselves their moment of death, if they should become demented. They think that the decline in personality and the vulnerability caused by severe dementia is shocking and unacceptable. In this context, some people consider euthanasia as a way to avoid total deterioration and vulnerability. Euthanasia of persons with dementia is allowed by the Belgian Act on Euthanasia as long as the person still has the required competency to express his actual euthanasia request. However, euthanasia of persons with severe dementia, as decreed in an advance euthanasia directive (AED), is not allowed in Belgium. Bills have been put forward in the Belgian Parliament to extend the current Act on Euthanasia towards persons suffering from severe dementia. In this contribution, we discuss some ethical and practical dilemmas regarding euthanasia in persons with severe dementia based on advance euthanasia directives. The main question is: Are advance euthanasia directives (AED) to be considered as dignity-enhancing care instruments to overcome the vulnerability of persons with severe dementia. Two main approaches to AED will be discussed. The principlist oriented or the ‘precedent autonomy’ approach on the one hand and the relational care oriented or ‘experiential interest’ approach on the other hand. We conclude our contribution with a critical ethical evaluation of euthanasia care practices in persons with severe dementia.

**P18.5. Is work stress in providing end of life care in a care home a cause for concern?: A Qualitative Study**

**VANDREVALA Tushna, ROSE Charlotte**

Background: Stress and burnout in care home staff has been well established, due to their direct contact with vulnerable older adults, job conditions and low pay. This has resulted in high staff turnover, psychological and physical impacts to the carer. With life expectancy in the UK increasing, many older people with dementia are likely to live and die in a care home. Providing care at the end of life compounds the expectations placed on carers and the psychological impacts of working in palliative care for care home staff are unknown. The aim of the current study was to investigate the ways in which care home staff experience working with people with dementia at the end of life and how this may contribute to their stress and burnout.

**Method:** A qualitative approach was employed and 15 care home staff who worked in dementia suites within residential care home, were interviewed. Thematic Content Analysis was used to analyse the data. **Findings:** Care home staff perceived the physical aspects of caring for people with dementia as contributing to their workload, especially as there was little time to accommodate the patient’s needs. Frequent encounters with death, being unable to reduce suffering for the patient and their families and the feeling of helplessness, particularly as they have built established emotional bonds, contributed to the emotional labour experienced by staff. Despite the many psychological impacts of working in palliative care, high job satisfaction was reported. **Discussion:** The implications of the environmental and individual characteristics in the process of work-related recovery will be discussed, particularly focusing on the lack of coping strategies and resources that are in place to support staff. Suggestions will be made for potential intervention to prevent negative health outcomes (compassion fatigue, vicarious traumatisation and burnout) due to increased work-related demands.
P19.2. How is learning and maintaining know-how related to technology experienced by people with dementia?

NYGÅRD Louise, ROSENBERG Lena,

Introduction: People with dementia are expected to manage everyday technologies such as cell phones, cash machines and remote controls, and new technologies to support them are continuously developed and introduced. But to be able to use technology, ability to learn new and maintain former know-how as well as to solve problems that occur when using technology is required. Most research on learning in the field of dementia has studied teaching approaches while little is known about learning as experienced and undertaken by those who learn, i.e. people with dementia.

The aim of this study was to explore the lived experience of learning related to technology among people with mild to moderate stage dementia.

Method: Seven persons with dementia were interviewed in-depth, and data were analysed with a phenomenological approach.

Results: Preliminary findings show how the participants positioned themselves in the technological landscape, and the process of self-initiated learning and maintaining know-how was characterized by a struggle to maintain the everyday flow of doing. Learning and technology were given different meanings by participants, and they used different ways of learning; for example, relying on previous knowledge, on support from others, on technology itself, or belonging to a learning context.

Conclusions: The findings suggest that we have much to gain from a better understanding of how people with dementia strive to learn and maintain skills and knowledge that they have related to technology. This is particularly important as learning seems to be undertaken by using other approaches than those employed in current teaching methods. The necessity of learning particularly stands out when it comes to the interaction with the current multitude and ever-changing designs of everyday technologies and interactive systems, including assistive technologies developed to support people with dementia.

P19.3. How older adults with mild cognitive impairment relate to technology as part of and potential support in everyday life

HEDMAN Annicka, LINDQVIST Eva, NYGÅRD Louise

Existing everyday technology as well as potential future technology may offer both challenges and possibilities in the everyday doings of persons with cognitive decline. To meet their wishes and needs, the perspective of the persons themselves is an important starting point in intervention planning. The aim of this study was to explore how persons with mild cognitive impairment relate to technology as a part of and as potential support in everyday life – both present and future.

Qualitative in-depth interviews with six participants aged 61-86 were conducted and analyzed, using a grounded theory approach. The findings describe the participants’ different ways of relating to existing and potential future technology in everyday doings as a continuum of downsizing, retaining, and updating. Multiple conditions in different combinations affected both their actions taken and assumptions made towards technology in this continuum. Both when downsizing doing and technology use to achieve simplicity in everyday life and when striving for or struggling with updating, trade-offs between desired and adverse outcomes were made, challenging take-off runs were endured, and negotiations of the price worth paying took place. In conclusion, our findings suggest that persons with mild cognitive impairment may relate to technology in various ways to meet needs of downsized doing, but are reluctant to adopt video-based monitoring technology intended to support valued doing. Feasibility testing of using already-incorporated everyday technologies such as smartphones and tablets as platforms for future technology support in everyday activities is suggested.

P19.4. Can everyday technology use predict need of support to live in the community among older adults with cognitive impairments?

RYD Charlotte, NYGÅRD Louise, MALINOWSKY Camilla, ÖHMAN Annika, KOTTORP Anders

Introduction: The number of older adults with cognitive impairments that affect the ability to live independently in the community is increasing. To identify and provide support to those in need is beneficial for the individuals as well as for the society. Increasing use of everyday technology (ET) has facilitated daily life but also made it more demanding. Amount of ETs perceived as relevant and perceived difficulty using ET has been proven to identify functional impairments among older adults with mild cognitive impairment (MCI) or mild stage Alzheimer’s Disease (AD) but if these measures can predict level of needed support to live in the community has not been explored.

Aim: To explore if amount of ETs perceived as relevant and perceived difficulty using ET can predict level of needed support to live in the community among older adults with mild stage AD or MCI.

Method: Participants were 69 older adults with MCI or mild stage AD. Levels of ETs perceived as relevant and perceived difficulty using ET were included in two logistic regression models aimed to predict level of needed support.

Results: In the model aiming to discriminate between participants that were independent from those who were in need of support the perceived amount of relevant ETs had a significant effect on the outcome. In the model aimed to discriminate between participants that needed maximal or moderate support from those that were independent or in need of minor support the perceived ability to use ET had a significant effect on the outcome.

Conclusion: Amount of ETs perceived as relevant and perceived difficulty to use ET are both useful for predicting need of support in daily life and complements each other in predicting different levels of need among the participants.
P20.1. Public policies and research about dementia: interdisciplinary reflections for improving care

DESANA Marie-Odile

France Alzheimer has always been aware of the stakes of research both for understanding the disease and its causes and for the development of therapeutic strategies and care process solutions. As such, the association has always given high priority to research since its beginnings.

It has always been particularly committed to fundamental and clinical research and participates in scientific progress by contributing one million euros each year to medical and human and social sciences research.

However, supporting research is not the sole responsibility of the associative field. It belongs to society as a whole, starting with public authorities. Indeed, three million French are concerned. And in light of the worrying projections, research is more than ever a public health issue. Some public policies have been implemented these past few years and have yielded results, but they need to be sustained and intensified.

For its 30th anniversary, France Alzheimer and related diseases is organizing, on May 21st 2015, a one day convention to assess progress and identify the challenges of research for the years to come. As we are convinced that it is the interaction of various fields of study which enables the efficient development and constant improving of the care process for those suffering from Alzheimer’s disease, our Association wishes to use this convention to promote an interdisciplinary and decompartmentalized approach. We will therefore attempt to establish the reciprocal links between research and public policy and will reflect on how they can both affect and complement each other.

Two central points will be addressed:

- The prevention of Alzheimer’s disease and public policy challenges: current state of research progress.
- The role of human and social sciences in the daily care of the sick and their families.

This convention is geared towards all parties involved in research: political and institutional players, members of public administration, researchers and academics, major associations and federations, private sector sponsors, Association donors.

Review of the day’s talks and debates and summary of main learnings.

P20.2. The national alliance for people with dementia

JANSEN Sabine

On World Alzheimer’s Day 2012 the German ministers for health and senior citizens initiated the National Alliance for People with Dementia. This is part of the “Demographic strategy” of the German government.

Participants of the National Alliance are different stakeholders from medical organisations, insurances, welfare organisations, care organisations and so on. The German Alzheimer Association was asked to cooperate as a co-chair besides the two ministries. Within two years activities in four fields of action were defined by the members of the alliance. These are information and research, public awareness, support of people with dementia and their caregivers and improvement of the care system for people with dementia. The implementation has started and a monitoring process has been developed.

To get people with dementia involved in the working process of the alliance the German Alzheimer Association has organised a participation process with members of the groups for people with early onset dementia.

P20.3. Croatian Alzheimer Alliance – powerful instrument in obtaining consensus on Strategy to fight Alzheimer’s disease and other dementias

MIMICA Ninoslav, KUŠAN JUKIĆ Marija

In order to develop a common national strategy to combat Alzheimer’s disease and other dementias we believe that the best and most effective way was to form an alliance of interested groups, which would develop and adopt that basic consensus document. Croatian Society for Alzheimer’s disease and Old Age Psychiatry, CroMA and Alzheimer Croatia were the main initiators and endeavoured to gain more members to Croatia Alzheimer Alliance (CAA). The initial public invitation to join the CAA was sent to all interested parties, and the associations listed below have joined the CAA: Croatian Society for Clinical Pharmacology and Therapy, Croatian Society for Neuroscience, Croatian Association of Palliative Medicine, Croatian Society for the Protection and Promotion of Mental Health, Croatian Neurological Society, Croatian Psychiatric Association. The draft proposal of “The Croatian Strategy for Fight Against Alzheimer’s Disease (2015 – 2020)” was assembled by members of the Croatian Society for AD and Old Age Psychiatry and Alzheimer Croatia, enveloped the national specificities on the basis of the existing plans of other countries taking into account the recommendations and advices of Alzheimer’s Disease International and Alzheimer Europe. The draft of strategy was published in the congressional supplement Neurologia Croatica and for the first time was presented and discussed on round table during CROCAD-14 in Brela, Croatia. The second public presentation was during national congress of psychiatrists in Zagreb.

At the moment, altogether, 21 professional associations and NGOs joined the Croatian Alzheimer Alliance. The public discussion will go on during the first half of the year 2015, when hopefully the final text of the Croatian National Strategy for Combating AD will be adopted and published in Croatian and English, to make it available for other countries in the world, especially those from the European Union.
P20.4. With public campaign to National Plan

LUKIĆ ZLOBEC Štefania

Up to 2010, the field of dementia in Slovenia was not systematically organized and the plan was not even discussed. In 2010, intensive efforts to implement the national plan for dementia were launched. I’ve became involved in the subject when my husband fell ill with Alzheimer dementia before 50 years of age, and with the two specialists who were treating him we discussed the necessity to implement the national plan on dementia. We gained support from the Parliamentary Health Board. As a result, we got support also from the Minister of Health and he issued a decree in May of 2010 to establish a working group for the preparation of the national plan on dementia.

What we learned from the Alzheimer Europe lunch debates in Brussels was that a wide public campaign is necessary to prepare the national plan. Spominčica in all these years through all its activities (very successful and nationwide Alzheimer Cafés, support groups and education programs for carers, Spominčica magazine ...) promoted the necessity and urgency of the national plan. We succeeded to raise awareness about dementia and de-stigmatization of the disease in general. All our activities are always accompanied by wide media publicity, especially on radio, TV, printed media and internet. In this way, we opened the space and made dementia more recognizable and the society more friendly to dementia.

The preparation of the plan is in its final phase. In the working group for the national plan on dementia of 10 people there are different professionals (psychiatrists, neurologists, GPs and representatives of Spominčica and representatives of the Government). All our 8 MEPs signed the Pledge that dementia becomes the priority of public health and they support our endeavors for the national plan. We also gained support from the President of the Republic of Slovenia, Borut Pahor. The necessity of having the national plan on dementia is our priority and we hope that we are now really near to it.

P20.5. National opinion survey on dementia: knowledge, attitudes and beliefs

MACHADO DOS SANTOS Pedro, PAUL Constança, NEVES Sofia, PORTUGAL Cristina, CARVALHO Alvaro

Objective: This national survey main goal was to characterise and analyse beliefs, knowledge, and attitudes of the Portuguese population regarding dementia in a comparative perspective (national and international level). Moreover the study aimed at identifying and compare the views of general public, health professionals and parliament members, to inform and support mental health research and policy making.

Method: An advisory group including academics and representatives of the Mental Health National Program was set up to draft the survey questions, based on previous researches. The survey was uploaded online on the Directorate-General of Health website and a link sent to related institutions and shared on social networks. The survey was cascaded by inviting recipients to further share it. Preliminary data collected between 10 December 2014 and 20 January 2015 were analysed, from a national sample of adults (age 18 and over).

Results: 951 responses were included. 71.9% of respondents were aged under 45, 75.5% were female, and 34.0% were health professionals. Nearly half of the respondents (44.9%) knew someone with dementia due to professional reasons, and 36.1% have or had relatives with dementia. Among a list of eight diseases dementia was the third biggest health fear after cancer and stroke. Around a quarter of the subjects (26.1%) said dementia was the condition they feared the most. Almost one third of the sample (32.7%) believes there is currently a reliable diagnostic test to determine early stages of dementia. Results also reveal that over 92.7% of respondents in Portugal say that if they were exhibiting confusion and memory loss, they would want to see a doctor to obtain a diagnosis. Over 98.2% would want the same if a family member were exhibiting those symptoms. Nevertheless, nearly a quarter of the respondents (26.9%) considered that most people who live in their community believes that people with dementia must leave/stop to attend ceremonies and social parties. According to the respondents point of view, only 7.3% of people in their community consider that dementia is a fatal disease, but about half (52.6%) believe that it causes much suffering to the sick person. 62.0% that it is a condition that causes greater social stigma in comparison to other diseases, and 92.8% that it is a disease that brings a great burden to the family.

Conclusions: The survey results will provide key information for evidence-based decision-making and contribute to a more efficient allocation of available health resources for dementia care. While building up on international learnings, the availability of national data will contribute to refine key areas for intervention and to establish priority actions in dementia care policy, including awareness-raising, education, prevention and treatment.

P21. Research opportunities in the Mediterranean Region

TOUCHON Jacques, GOUIDER Riad, NAJA Nabil

The significant increase in the number of people with Alzheimer’s disease and related disorders worldwide is alarming. Over the next 20 years, it is estimated that this increase will be much steeper in low and middle income countries compared with high income countries. The countries outlining the Mediterranean are united by historical, geographical and cultural links, but more importantly by common values of solidarity. There is still little knowledge about the problems surrounding Alzheimer’s disease, which remains underestimated and insufficiently documented in many Mediterranean countries, especially in North Africa. This situation is set to have a dramatic impact on human, sanitary and social society across the Mediterranean.

Upon the initiative of the Monegasque Association for research on Alzheimer’s disease (AMPA), a Mediterranean Alzheimer Alliance (MAA) was launched in April 2013 in Marrakech. This network
practices. 5. To put forward recommendations in order to make sure that Alzheimer’s disease becomes a priority in the Mediterranean.

Upon the creation of the MAA’s scientific committee, this session will be devoted to research on Alzheimer’s disease in the countries outlining the Mediterranean. It will present the strengths and resources for research in this region with particular emphasis on the possibility of focused research on prevention, nutrition and psychosocial interventions.

This session is organised by the Mediterranean Alzheimer’s Alliance. The MAA currently regroups 17 countries (Algeria, Croatia, Cyprus, Egypt, France, Greece, Italy, Lebanon, Libya, Malta, Monaco, Morocco, Portugal, Slovenia, Spain, Tunisia, and Turkey).

The MAA is composed of Alzheimer associations, scientific experts and health care professionals from the Mediterranean region. This network aims 1. To help Alzheimer actors in the Mediterranean area develop their initiatives, 2. To identify the needs and specificities of this region, 3. To encourage future partnerships between associations, scientists and academics, 4. To share and exchange knowledge and
**Slovenian Sessions**

**SL1.1. Zagovorništvo za osebe z demenco in njihove svojce**  
**KRIVEC David, LUKIČ ZLOBEC Štefanija**

V združenju Spominčica – Alzheimer Slovenija s svojim delovanjem, ki je usmerjeno v informiranje o demenci in destigmatizacijo boleznih, smo v okviru svojega svetovalnega dela zaznavali potrebo po zagovorništvu za posameznike z demenco. Posamezniki z demenco, njihove družine in tisti, ki jane skrbi, morajo imeti dostop do informacij, izobraževanja in podpore, ki jim omogočajo najvišjo možno kakovost življenja in ustrezno načrtovanje prihodnosti.

Družba mora biti seznanjena s problemi oseb z demenco in njihovih svojcev in da prisluhne njihovim potrebam in jih skuša na čim boljši možni način rešiti. Prek zagovorništva si prizadevamo, da imajo osebe z demenco možnost in priložnost izraziti svoje želje glede zdravljenja, pravnih in finančnih zadev ter glede oskrbe v napredovalnem stadiju bolezni. Na vse to opozarja Spominčica kot prva zagovornica pravic oseb z demenco in njihovih svojcev v Sloveniji, v okviru priporočil Alzheimer Europe in v skladu z Glasgowsko deklaracijo.

Na področju zagotavljanja potreb po socialnem zagovorništvu za obolele za demenco in njihove svojce, ki imajo pogosto težave z reševanjem svoje stiske. Te izvirajo iz slabega dostopa do ustreznih informacij, stigmatizacije demence v družbi in so toliko večje zaradi nerazumevanja ali slabega poznavanja problematike s strani strokovnjakov in strokovnjakinj v drugih organizacijah ter slabega medinstičnega povezovanja in sodelovanja. S svojim delovanjem se trudi za spoštovanje pravic in etičnost ravnanja z osebami z demenco in njihovimi svojci. Kot je zapisano v Glasgowski deklaraciji (2014), mora imeti vsak posameznik z demenco:

- pravico do pravočasne diagnoste,
- pravico do kakovostne obravnave po postavljeni diagnozi,
- pravico do individualne, koordinirane in kakovostne obravnave ves čas bolezni,
- pravico do enakovrednega dostopa do zdravljenja in terapevtskih ukrepov in
- pravico do spoštovanja v skupnosti.

**SL1.2. Mlade osebe z demenco**  
**SPANJA Mihela, LUKIČ ZLOBEC Štefanija**

I have been working for the Slovenian Alzheimer Association Spominčica for more than 5 years. I have started to work in this field when my husband was affected by Alzheimer's dementia, not yet 50 years old. He was a public person, deputy in Slovenian Parliament, human rights activist, translator, poet and Slovenian ambassador in Brussels. Unfortunately, the diagnosis was established very late, because he was supposed to be too young for such a disease. Soon after coming back from Brussels where he was the ambassador of the Republic of Slovenia, his behavior patterns slowly changed. From an extremely energetic person, he became completely passive. He had problems finding words, had difficulties speaking and became inactive in every aspect. In 2012, when he was in the last stage of his illness, I decided to speak about his condition in public and thus raise the public awareness about dementia and young patients. There are not many people with dementia capable of expressing their feelings and will. Therefore, a Working Group for Carers of People with Early Onset Dementia was established to exchange experience and socialize.

**SL1.3. Demenci prijazno okolje: prostovoljno socialno delo**  
**VALIČ Sonja, PLANKO Sonja, DEVETAK Veronika, STRES Cristina**

Velik problem za osebe z demenco in njihove družine je socialna izključenost, ki se z napredovanjem bolezni še stopnji in se največkrat zaživi tako, da bolnik ostane sam, prepuščen sebi in svojem. Poslanstvo društva GO-Spominčica za pomoč pri demenci je ozaveščanje javnosti o demenci in s tem destigmatizacija oseb z demenco. V društvu želimo omogočiti osebam z demenco in njihovo zdravljenje v okolju, ki bo osebam z demenco naključeno in prijazno. Trudimo se izboljšati kakovost življenja oseb ter demenci in njihovih družinskih članov. Pri tem so nam v veliko strokovno pomoč zdravstveni in socialni delavci, zaposleni na oddelkih za osebe z demenco ter prostovoljci, ki so pripravljeni svoj prošti čas nameniti osebam z demenco tako v domovih starejših občanov, kakor v domačem okolju.

Društvo GO-Spominčica se je pred leti vključilo v projekt Prostovoljno socialno delo, ki ga izvaja Center za socialno delo v Novi Gorici. V projektu sodelujejo organizacije v domačem okolju: Društvo GO-Spominčica; Dom upokojencev Nova Gorica, Društvo za socijalno delavnost, Društvo za učinkovito delovanje družav, Društvo za socialno delavnost, Društvo za socijalno delavnost.

**SL1.4. Spominčica Šentjur in varne točke za osebe obolele za demenco**  
**STOPAR Mojca**


Prvi projekt z naslovom »Od Bohorja do Pohorja« je bil namenjen predvsem medgeneracijskemu sodelovanju. V okviru tega projekta je v Domu starejših Šentjur. Spominčica Šentjur je še posebej ponosna na 2 projekta:}

- Prvi projekt z naslovom »Od Bohorja do Pohorja« je bil namenjen predvsem medgeneracijskemu sodelovanju.
- Drugi projekt z naslovom »Prezgodnje demenco: zaščita oseb z demenco ter njihove svojce« je bil namenjen prostovoljci družbe.
SL1.5. Zagovorništvo nevroznanosti v Sloveniji: projekt Za zdnevu.

PS: Želim, da je članek predstavljen v slovenščini na slovenskem obolelim za demenco in njihovim svojcem. Naš cilj je, da še naprej nudimo podporo in izobraževanja ljudem

Cilj tega projekta je, da se v Celju vzpostavi Center za demenco. »Živeti z demenco«

Trenutno sodelujemo kot partnerji v norveškem projektu z naslovom: zainteresiranih zaposlenih v teh ustanovah. 2015 še nadaljujemo s podpisovanjem pogodb in izobraževanj pošte, Razvojne agencije Kozjansko. Podpisane so pogodbe in v letu 2015 še nadaljujemo s podpisovanjem pogodb in izobraževanj zainteresiranih zaposlenih v teh ustanovah.


SL2.1. Depresija pri demenci

PISLIJAR Marko

Diferencialna diagozna depresije in zgodnje faze Alzheimjeve bolezni lahko predstavlja resno klinično vprašanje. Depresija se kar v 40% pojavlja kot spremljajoči sindrom demence, pogosto v letih pred postavitvijo diagnoze demenca Alzheimjevega tipa. Večje epidemiološke študije kažejo po drugi strani, da imajo tudi bolniki z depresijo, ki se pojavlja v starejšem obdobju večje tveganje, da bodo zboleli za demenco. Bolnik z depresijo in spremljajočimi motnjami spoznavanj fizično-spiralni nesporazum, ki v naslednjih letih potrebuje intenzivnejše spremljanje spoznavnih sposobnosti oziroma razvoja demence.

SL2.3. Kako izboljšati in zapolniti vsakdan oseb z demenco

LUKNER Ana

Demenca prizadene posameznikove možganske celice, odgovorne za spomin, mišljenje, orientacijo, razumevanje ter sposobnosti govornega izražanja in presoje. Te motnje pogosto spremljajo spremembe čustvovanja, socialnega vedenja in motivacije. Osebe so ovirane pri vsakodnevnih aktivnostih, njihova sposobnost obvladovanja vsakodnevnega življenja je bistveno omejena. Svojci so ob večletni skrbi za bolnika izpostavljen velikim psihičnim, fizičnim in čustvenim obremenitvam in izgorevanju.

Predstavljena bodo inovativne prakse in uporaba raznih pripomočka za osebe z demenco, svojce ter inštitucije, ki so povezane z demenco (domovi, dnevni centri,...); med njimi so pripomočki za izboljšanje varnosti oseb z demenco, pripomočki za samostojno opravljanje vsakodnevnih opravil, pripomočki edukativne narave. Vse to služi temu, da imajo osebe z demenco aktivno zapolnjen dan, ki ga lahko čim bolj samostojno in aktivno preživijo. S temi inovativilnimi pristopi se tudi izboljša kakovost življenja svojcev, saj osebe z demenco lahko samostojno opravljajo priljubljena opravila. Izkušnje kažjo, da namenski tehnici in drugi pripomočki pomembno izboljšajo vitalnost oseb z demenco, njihovo varnost in pomembno prispevajo k upočasnjemu napredovanju demenco. Predstavili bomo naše izkušnje in doganjana na tem področju. Bistvo je, da se oloža in izboljša kakovost življenja osebam z demenco in svojcem ter da ozaveščamo družbo o demenco, ki je še vedno zelo stigmatizirana.

SL2.4. Plesno-gibalna terapija kot oblika psihosocialne pomoči starostnikom z demenco

ŠOŠTARKO Mojca

Plesno-gibalna terapija, utemeljena na načelu o povezavi telesa, duha in čustva, kjer se v posameznem gibanju odražajo vzorci njegovega razmišljanja in čustvovanja, je primerna oblika terapije za ljudi, ki imajo težave s kognitivno prizadetostjo in težki izrazijo svoje misli in čustva. Osebnost kljub kognitivnemu upadu ni prizadeta, plesno-terapevtski pristop pa se osredotoča na aktiviranje ohranjene sposobnosti in ustvarjanje okolja, ki spodbuja avtentično učinkovanje. Predstavljamo občaj preiskovanje z osebami ter z gostimi, ki upošteva specifiko slovenskih starostnikov glede na kulturno okolje. Astorji poročajo o korisni izboljšanju plesno-terapevtskih srečanj, učinkovitosti ter pripomočku za izboljšanje čustvenih izrazov. Izkušnje kažejo, da so osebe z demenco lahko samostojno in aktivno vključene v plesno-gibalne terapijske srečanja in pripomenejo lepoto in estetiko življenja.

SL2.5. Povezani v tišini – inovativne poti v oskrbi oseb z demenco

REBERNIK Klara, PADEN Ljubica, MILAVEC KAPUN Manja, CECUNJANIN Almina, DOMAJNKO Barbara

SL3.1. Pogled na epidemiološke podatke o demenci in z njo povezanimi boleznimi v Sloveniji

OIKONOMIDIS Christos, MACAJNA Anja, KONEC-JURIČIČ Nuša

Izhodišča: Naš cilj je oceniti stanje v zvezi s demenco in z njo povezanimi boleznimi v Sloveniji, proučiti raven in zanesljivost nekaterih epidemioloških podatkov ter predlagati rešitve za izboljšanje načina epidemiološkega spremljanja na tem področju.

Metode: Za izvedbo raziskave smo s pomočjo dveh podatkovnih zbirk zdravstveno podatkovnega centra Nacionalnega inštituta za javno zdravje (Znajdbo zdravstvene statistike in Zbirke spremljanja bolnišniških obravnav) zbrali in analizirali podatke kot pristop k pregledu stanja, od leta 2006 do leta 2012.

Rezultati: V letih od 2006 do 2012 je število končnih diagnoz (F00-F03+G30), postavljenih na sekundarni ravni zdravstvenega varstva, vsako leto konstantno naraščalo. Na ravni speciališčne zunanjiščniki zdravstvene dejavnosti je najpogosteje diagnosticirana oblika demence neopredeljena demenca (F03). Med opredeljenimi oblikami je najpogosteje Alzheimerjeva bolezen (G30). Na podlagi števila hospitalizacij lahko zaključimo, da je tudi v tej zbirki podatkov Alzheimerjeva bolezen najpogosteje oblika demence, zaradi katere so bili pacienti hospitalizirani. 

Zaključki: Na podlagi predstavljenih podatkov je razvidno, da je s tem obstoječi obseg zdravstvenih storitev za ljudi z demenco in z njo povezanimi boleznimi v Sloveniji, še vedno izhaja iz zahtev, da bi se toboljševala.

SL3.2. Raziskovanje potreb ljudi z demenco

MALI Jana

Skrb za ljudi z demenco in njihove sorodnike je vzajemna odgovornost vseh poklicev, ki sodelujejo pri oskrbi ljudi z demenco. Poseben poudarek socialnega dela je v odkrivanju potrebi ljudi z demenco, da bi oblike pomoči za ljudi z demenco in življenje sorodnikov z ljudmi z demenco, prilagodili njihovim potrebam, željam in ciljem. V središču pozornosti ni demerca, temveč človek, ki ima demenco, ki potrebuje veliko spodbud in razumevanje okolice, da lahko samostojno (preživi v skupnosti. Zaradi vseproščenega odklonilnega odnosa do demence in zapostavljanja ljudi z demenco je pomemben poudarek socialnega dela z ljudmi z demenco tudi krepitve moči ljudi z demenco, ko vendar tudi sorodnikov, ki za njih skrbi, saj se tudi sami pogosto soočajo z nesrečanjem okolice in odrivanjem iz vsakdanjega življenja. Usmerjenost na krepitve moči udeležencem omogoča, da prevzamejo odgovornost za lastna življenja, jim pomaga pridobiti samospoštovanje in spoznati vrednost lastnih izkušenj, a tudi subjektivno okrepi njihov položaj, jim omogoči vstop v različne in cenjene vloge, vsako leto konstantno naraščajo. Na podlagi štirih ravni življenja ljudi z demenco (prvič, izvedbene ravni življenja ljudi z demenco, težave v vsakdanjemu življenju, pomoč), drugič, ravni medsebojnih odnosov (odnosi z ljudmi, socialni stiki, socialne mreže), tretji, ekonomskih ravni (finančni stroški, sredstva za preživetje, stroški pomoči) in četrti, etične ravni (pravice ljudem z demenco, spoštovanje, stigma), bomo predstavili izkušnje življenja z demenco in z njo povezanih bistvenih dejavnih izskočno in v zgodovini, ki za njih potrebne, ali tudi stisnejo različne in cenjene vloge, vsako leto konstantno naraščajo, da lahko samostojno (preživi v skupnosti. Zaradi vsesplošnega odklonilnega odnosa do demence in z njo povezanimi boleznimi z ljudmi z demenco, prilagodili njihovim potrebam, željam in ciljem. We must focus our point of view from the individual to society and from elderly as a minority to the elderly as a healthy majority. Therefore we must implement new approaches that promote interventions focused on wellbeing, and are enhancing the possibility of individuals with dementia to reengage with society and live better, and active life as long as possible. Several studies have shown the positive effect of bibliotherapy on the severity of dementia symptoms and the quality of life, improving their self-esteem, and a sense of belonging, and their communication skills. However, despite the fact that bibliotherapy has positive effect on...
individuals with dementia, is rarely used as a therapeutic approach in Slovenia, especially when dealing with elderly with dementia. The aim of our study is first to gain better understanding of the influence that bibliotherapy has on the individuals with dementia, and second to find out what kind of literature is the most suitable for individuals with dementia, and third we would like to investigate, on the basis of our observations if bibliotherapy has any effect regarding social and daily functioning on the participants with dementia in a reading group.

SL3.4.  S skupnimi koraki k razumevanju podobe demence

PEČOVNIK Dalja

Center starejših Zimželen v Topolšici deluje po modelu gospodinjskih skupnosti. Od devetih bivalnih enot sta dve varovani enoti za osebe z napredujočo demenco. V domu lahko biva 150 stanovancev; dobra tretjina je oseb z demenco na različnih stopnjah. V skladu s poslanstvom Zimželena si prizadevamo za čim večjo vpetost v lokalno okolje z različnimi programi ozaveščanja javnosti in preventivne dejavnosti. V letu 2013 smo zastavili interni projekt Model ravnanja z osebami z demenco. Projektom skupino sestavljamo sodelavce interdisciplinarnih področij.

V dveh letih se je 40 zaposlenih iz vseh delovnih področij izobraževalo o ravnanju z osebami z demenco. Tesno sodelujemo z sorodniki stanovalcev, ki jih vključujemo pri zapisu biografije stanovalcev, s proti jih obveščamo o vseh spremembah in dogajanjih z njihovimi sorodniki.

Pri svojih in obiskovalcih zaznavamo stisko pri odnosih in življenju z osebami z demenco. Zato smo v letu 2013 oblikovali pogovor in sodelovali s oseb, ki jih obveščamo o vseh spremembah in dogajanjih. Vodite jih sodelavci z lastno izkušnjo v življenju z osebami z demenco in jih usposobili za vodenje pogovornih skupin.

V letu 2014 smo projekt nadgradili z odprtjem treh svetovalnic z demenco v Šaleški, Savinjski in Koroški regiji. Namen svetovalnic je, da se približamo ljudem na terenu, damo informacije in možnost individualnega pogovora vsem, ki si čudojo odgovore pri srečevanju z demenco.

Vodje svetovalnic so strokovne sodelavce Zimželenja, ki so v okolju, kjer vodijo svetovalnice, prepoznamo kot zaupanje vredne osebe. Izvajamo predavanja o demenci za ciljne skupine, ki se v različnih vsakodnevnih situacijah srečujejo z osebami z demenco (društva, humanitarne organizacije, socialni oskrbovalci na domu, policija, gasilci, poštni delavci,...).

Delovanje svetovalnic smo medijo podprli s članki, intervjuji za lokalne radio in tv medije, pripravili smo letak, plakat in brošuro, ki smo jih razdelili v zdravstvene domove, centre za socialno delo, knjižnice. Z Andražskim zavodom Slovenije – Ljudsko univerzo Velenje sodelujemo pri izobraževanju v programu NPK socialni oskrbovalci.
PO1.1. The influence of empathic concern on views of the humanness of persons with dementia

MCFADDEN Susan, MIRON Anca, NAZARIO Amanda, BUELOW Jennifer, SWENSON Nicole, FEDRAN Christina

We tested whether elicitation of empathic concern through imagining the situation of a person with dementia would increase the amount of evidence of ability impairments needed for individuals to conclude that someone with dementia fails to meet standards of humanness. We used Haslam’s two-factor humanness model (Haslam, 2006) to assess human nature standards (HN Standards; evidence of human nature such as emotional responsiveness, interpersonal warmth, cognitive openness, agency, and memory) and uniquely human standards (HU Standards; evidence of uniquely human characteristics such as moral sensibility, rationality and maturity). Participants were shown a photo of a woman with dementia, and then were randomly assigned to imagine her situation (imagine-other condition), remain objective and detached about her situation (objective/detached condition), or were not given further instructions (control condition).

Participants in the imagine-other and control conditions reported greater empathic concern for the woman compared to the objective/detached participants, both ts(103)>2.25, both ps<.03. Participants in the imagine-other condition asked for more evidence of HN and UH characteristics in order to conclude that the woman failed to meet standards of humanness, compared to objective/detached participants, both ts(103)>2.25, both ps<.03. Participants in the control condition also asked for more evidence of HN (p=.08) and UH characteristics (p<.05) in order to conclude that the woman failed to meet standards of humanness, compared to the objective/detached participants. Indirect tests revealed that empathic concern mediated the effect of the imagine-other (i.e., perspective-taking) manipulation on HU standards, but not on HN standards. These findings show the role of empathic concern in how people perceive the humanness of persons with dementia and suggest that those who are encouraged to remain objective about and detached from the situation of persons with dementia are more inclined to dehumanize them.

PO1.2. Making a difference: Can ‘Dementia Friendly Communities’ increase awareness of dementia and help people affected by the condition to feel supported and valued within their community?

HEWARD Michelle, CUTLER Clare, INNES Anthea, HAMBIDGE Sarah

A Dementia Friendly Community (DFC) is a community where people with dementia are empowered and feel confident, knowing they can contribute and participate in activities that are meaningful to them. In Dorset, seven independent DFC initiatives were created to increase awareness of dementia. The project was evaluated using a mixed methods approach, including questionnaires, interviews and focus groups. The evaluation examined the experiences of people with dementia and their carers, members of the public, Project Workers from the localities, and businesses that became involved, during the first year of activity. Within each locality an increase in dementia awareness raising activity was noted. A successful mechanism for raising awareness within a local community was to provide one person with information about dementia to disseminate to others.

Although, limited involvement of people with dementia and their carers meant it was challenging to ensure their perspectives were included. For DFC’s to develop an inclusive, community focused approach to becoming dementia friendly, it is suggested that they follow guidance that identifies 10 areas of focus: involvement of people with dementia, challenge stigma and build understanding, accessible community activities, acknowledge potential, ensure an early diagnosis, practical support to enable engagement in community life, community-based solutions, consistent and reliable travel options, easy to navigate environments, and respectful and responsive businesses and services. By raising awareness of dementia within communities, DFC’s can make a difference to people affected by the condition. However, establishing networks and connections within a community takes time and is an on-going task for all DFC’s to contend with.

PO1.3. Dementia detectives: Busting the myths surrounding dementia in schools

OYEBODE Jan, PARVEEN Sahdia, ROBINS Jan, GRIFFITHS Alys

The national dementia strategy in the United Kingdom is focused on reducing the stigma attached to dementia through public awareness. This has led to a number of dementia awareness initiatives that aim to reduce the negative connotations associated with dementia and promoting positive imagery and accurate information to the public. Most of the dementia awareness done in the UK has focused on adults. To develop and sustain dementia friendly societies, further work is required with young people. Dementia Detectives is a one hour session dedicated to promoting dementia awareness and is designed for secondary school students aged 14 to 16 years. The main aims of Dementia Detectives are to demystify the condition in order to encourage a positive attitude towards those living with dementia and inspire young people to play an active role in ensuring they live in a dementia friendly society. Dementia Detectives has been piloted with 38 students in a secondary school. Students rated their perceived level of knowledge pre and post session on a 10 point Likert scale. Students’ perceived knowledge improved from an average score of 4.5 to 8. On a 10 point Likert scale students rated the session 7.8 for ease in understanding the information presented, and 7.9 for overall enjoyment. Thirty six of the 38 students said they would recommend the session to their friends and other people. Students highlighted the ‘best bits’ of Dementia Detectives as: learning about types of dementia, group discussions, the videos and discovering
PO1.4. We and the others: How residents in elderly care facilities perceive residents with dementia

LEVICKA Katarina, VNUK Ivan

The purpose of this poster is to closer how residents with dementia are perceived by the rest of the residents in social care facilities. Slovakia is still a lack of specialized facilities for people with dementia, particularly with Alzheimer's disease. People with dementia are therefore placed in other types of facilities that are available, mainly elderly care facilities. However, into these facilities people with dementia are placed along with the other residents. Despite the efforts of most elderly care facilities to generate at least a separate part of the building designed specifically for people with these specific needs, it is not always possible to provide the people with dementia with ideal conditions. As a result, some residents with dementia are in daily contact with the populations of facility that do not have similar specific problems or needs. Their perceptions and behavior towards the residents with dementia is often problematic. Negative approach, accompanied by misunderstanding and rejection is quite common.

This poster therefore focuses on how non-demented residents from residential care perceive residents with dementia. We also describe the possibility of working with the residents so that their perception of residents with dementia would be more positive and bring change in their attitudes and behavior. We discuss results of specific educational-integration program for the residents used in our elderly care facility.

PO1.5. Alzheimer: the voice of people living with dementia

DESANA Marie-Odile

Over the past few years, as diagnoses are made increasingly early, as public information is more and more accessible, as patients are not afraid to speak out anymore... the public’s view of people living with dementia has notably evolved.

The newly acquired visibility within society, stimulated by the means of expression and speech which are now available, has encouraged the forming of new social representations and a change of society’s perception vis-à-vis the illness. Namely, it has contributed to recognize the people living with dementia as fully legitimate actors whose consent, as well as freedom of choice and expression must be systematically researched.

Far from being reduced solely to the disease, people living with dementia are finally progressively recognized for what they are, and continue to be in spite of the illness: full-fledged humans modeled by their life history, their experience, their personality; people who make themselves fully involved in decisions which concern them; people who wish to make their voices heard and express their experience of the illness and their needs.

France Alzheimer and related diseases has always worked for the voice of the ill to be heard and respected regardless of the form it may take, and has always considered it to be crucial to factor it in the care process. As such, the various actions suggested by the associations in our network attempt to encourage and develop all possible means of communication: language, speech, gestures, attitudes...

For World Alzheimer’s Day 2015, our Association again wishes to shed light on the topic of the people living with dementia speaking out, being heard, having their choices, desires and their will respected, throughout their care, from the diagnosis to end of life.

Whether seen from a sociological, psychological, ethical or legal standpoint, habits have evolved. A growing number of expression outlets, improved social inclusion, increased participation opportunities, greater respect for the identity of each person living with dementia, a more personalized care pathway... We will review existing notions, concepts and structures.

The people living with dementia are speaking out, let us listen! Let us give their voice its due status.

PO1.6. The potentiality of expressive and sign language

De ROSA Giuliani, FRANCONE Caterina, SOMMELLA Francesca, De ROSA Guglielmo, BRUNO Patrizia

Introduction: The association A.M.N.E.S.I.A., Italian acronym for Neurogeriatric Diseases and Alzheimer Syndrome Association, has amongst its main objectives, that to provide support to the familiar, informal and institutional network creating a system culture for taking care of the Neurogeriatric pathology. Amongst the activities that the A.M.N.E.S.I.A. team offers to people affected by Alzheimer, there are artistic laboratories such as the education to theatricality. The pedagogical value of the theatrical experience allows to reveal the active energies of the human expression and to educate the elderly to creativity.

Purpose: The objective of the artistic-theatrical laboratory is found in the expressive action, transforming it into an auto-pedagogical process, and one of development of one’s own creative acting. Hence the objectives have located in the education to the development of active energies of the human expression and to educate the elderly to creativity.

Materials and methods: The encounters took place in the home of one of the members of the group. Fundamental was the actualisation of the process of individual and collective empowerment. They started with social activities and viewings of film scenes with Charlie Chaplin, actor to be observed, picked by the activities’ participants. Finally, there was a re-enacting of a “wordless” scene through the reading of simple sentences to express in sign language.
PO1.7. Antidepressants for the treatment of agitation and aggression in Alzheimer’s disease

ZMUC VERANIČ Lea

Background: Behavioral and psychological symptoms (BPSD), especially aggression and agitation are a common accompaniment of dementia and are often responsible for a large share of suffering of patients and caregivers. There are many different treatment options available for the BPSD treatment. Antidepressants are often used in patients with Alzheimer’s disease (AD), but efficacy in the treatment of aggression and agitation is not well documented.

Subject and methods: A 6 week prospective, structured clinical trial was conducted in AD patients. 35 patients were recruited and patients were divided to escitalopram group, where the maximum daily dose of escitalopram was 10 mg in the morning and standard treatment group (STG), where treatment of BPSD was standard. Primary efficacy measures were the 10 item Neuropsychiatry Inventory (NPI) and change from the baseline in the Cohen-Mansfield Agitation Inventory (CMAI).

Statistical analysis: SPSS for Windows was used to manage data. Counts (percentages) for categorical variables were used, as well as mean (SD) for normally distributed continuous variables. ANOVA was conducted to evaluate scores from baseline over week 6 and mixed model analysis was used to compare the two treatment groups over the total follow up period.

Results: Demographic and clinical characteristics at baseline were similar across the two groups. Improvement of aggression and agitation according to NPI and CMAI scores has been shown in escitalopram and standard treatment group from baseline to week 6. No statistical difference was found in the efficacy of escitalopram and standard treatment group.

Conclusion: Escitalopram could be an option of the treatment of aggression and agitation in AD patients.

PO1.8. Ethical problem: dignity and self-determination of people with dementia against “locking up” these people in the name of their safety

KOBENTAR Radojka, ZORC MAVER Darja

Theoretical background: The societal resources for the care of the elderly population, especially those with cognitive disorders, do not guarantee the necessary support for dementia patients’ quality of life. The new treatment paradigm hence encompasses the plasticity of aging, subjective feelings and individual characteristics of the individual.

Methods: The quantitatively analyzed data was chosen by direct observation, polling and patient documentation research. The eligibility criteria for the subjects were, minimum age of 65 years, living in a nursing home a diagnosis with dementia. The reliability of the scales was verified with the alpha-Cronbach testom. The level of statistic reliability was p=0.05.

Results: The sample of 233 patients, included only 15% of men. The sample average age was 86 years [± 6,3 years]. Patents that have fulfilled their social eligibility criteria for the subjects were, minimum age of 65 years, living in a nursing home a diagnosis with dementia. The reliability of the scales was verified with the alpha-Cronbach testom. The level of statistic reliability was p=0.05.

Discussion: The comprehensive understanding of the patients’ problem must also account for multimorbidity, chronicity and the individual personal characteristics of the elderly, which also depends on the level of self-reliance and independence. In the future, more than a purely medical approach we will need to consider changing the current concept of working with patients.
PO1.10. Dementia Outcome Measures: charting new territory

MOUNTAIN Gail, MONIZ-COOK Esme, OEKSNEBJERG Laila

This project is funded through the EU Joint Programme for Neurological Diseases and involves members of Interdem (www.interdem.org). It is based in the understanding that there is a need for further work on outcome measurement for psychosocial dementia research that embraces new ideologies and practices in dementia care. The project which will complete in 2015 has been working with this extensive agenda. Methods have involved

- Reviews of the literature within relevant domains
- A series of expert, consensus workshops with members of Interdem (including participation by early stage career researchers)
- Collaboration with other research groups and individuals working in this area
- Pan European consultation with people with dementia about what they consider are the important questions to be asked

Results include:

Recommendations regarding which existing outcome measures should be used for psychosocial research, thereby updating the contents of a well cited paper published in 2008 (see Moniz-Cook et al, Ageing and Mental Health)

Consideration of what should be measured in the future taking into account the growing movement to hear the voices of people with dementia

Views of people living with the condition; both in terms of how outcome measures are currently applied and what should be taken into account.

Outputs:

The work is yielding three publications:

- An update of the 2008 paper
- A review of need for new measures to reflect new measurement domains, including recommendations from what exists already
- An account of the process and outcomes of the pan European consultation with people with dementia and their supporters.

PO1.11. Detection of disorientation to enable situation-aware navigation assistance

KOLDRACK Philipp, HENKEL Ron, TEIPEL Stefan, KIRSTE Thomas

Engagement in cognitively stimulating activities is one of the most effective measures against the decline of cognitive abilities due to dementing disorders today. While outdoor and social activities are cognitively challenging and provide emotional support at the same time. Alzheimer’s disease as the most frequent cause of the dementia syndrome however early affects skills for spatial orientation and simultaneously impedes planning and error compensation abilities. These are necessary to overcome disorientation in unfamiliar environments. People with dementia progressively limit their life-space and diversity of activities in reaction to growing security concerns. It is desirable to provide appropriate guidance in disoriented situations to avoid dangers, while not, in addition, complicating normal mobility in order to maintain a person’s life-space, activity spectrum and cognitive health.

We intend to realize a detection system for disoriented behavior in outdoor situations, that is able to discern different types and causes of disorientation, building on knowledge based computational techniques for human activity recognition, called Computational State Space Models (CSSM). The application of CSSMs depends on a set of sensor data assessed under realistic conditions and labeled with a description of the underlying behavior. This serves as a ground truth for model building and training of its statistical parameters.

We performed 10 sensor and diary based assessments of the everyday mobility of study participants with MCI or mild dementia due to Alzheimer’s disease, each lasting for about 4 days. Additionally, 4 accompanied walks along a predefined route in an urban environment took place and are continued until 14 runs are completed. Here the participants have to navigate back to the point of origin, drawing on their navigational skills. The display of disorientation is analyzed by an accompanying psychologist and the additional recording of biofeedback enables to identify stressful environmental influences.

The result of preliminary analysis is an ontology for the description everyday mobility, comprising 66 behaviors organized in 8 orthogonal classes. The ontology is applied to annotate the sensor protocols and will soon enable to comprehend and map the causal structure of mobile behavior onto a CSSM for its detection.

PO1.12. The fundamental drama of mankind is repeated in the drama of dementia

FRETER Björn

Man, as we can still ascertain with the aid of Kant’s insights, suffers from a very particular fate, namely that of being besieged by questions which he cannot answer, such as those relating to the existence of God etc. These questions cannot be answered, since they necessarily exceed the limits of human understanding, but they cannot be ignored either.

The ability to pose questions like these is a key characteristic of the fundamental existential situation of mankind. Considerable effort is required to come to grips with this existential determination. Every person must find his or her own particular method of coping with such questions. This makes up a significant part of the human maturing process.

A person with dementia, having already found his or her personal solution to the problem of these unanswerable questions, radically stumbles into this existential situation once again. The tragedy of this repetition is that the people with dementia can only make limited use,
PO1.13. Perceptions and image of person with dementia yesterday and today in Bosnian society

KUCUK Osman

These are just the names of the chapters!!!!

- Dementia in the Bosnian society
- Traditional acceptance of people with dementia
- War and migration of population
- Acceptance of persons with dementia today
- Number of people with dementia in Canton Sarajevo
- Home care methods for persons with dementia
- Help society

PO1.15. Air travel and dementia

MUKHERJEE Sujoy, SAHAY Anju

Travelling has become an integral part of modern life but it can be tricky if the passenger is living with dementia or one is travelling with such an individual. This is particularly challenging when the journey involves air travel, often long haul flights. The prospects of going through noisy and busy airports, long queues at check-in and security, several hours in a crowded aircraft, landing in an unfamiliar place and the difference in time zones can all lead to confusion and behavioural disturbances among people with dementia.

It was estimated that in 2010 over 35 million people lived with Dementia across the globe and the number is expected to double every 20 years. It is increasingly common to see such people travelling by air and to make such journeys safe and comfortable should be a key element of our drive to a Dementia friendly society and world.

However, research in this area is still surprisingly limited. We have explored the physiology of flying and its potential impact on people living with Dementia, challenges and helpful advices for people with Dementia and carers, issues around policies and stakeholder participation, indicators of good practice and directions for future research.

PO1.16. Spreading care through the community

DEPONTE Antonella, PACCO Giovanna, BONIFACIO Teresa

Once diagnosed, Alzheimer’s disease provokes a great distress in the person and in his/her family. Such a distress involves psychological, physical, emotional aspects and can be dramatically enhanced by the difficulties in finding the relevant information about services and assistance, by the social stigma associated with dementia, by the fragmented composition of the network of the resources. Bureaucratic and helping tasks sum up to the disruptive impact that the diagnosis has per se, making harder the possibility for people with dementia to remain at their own homes.

A model of inclusive care is proposed here, originating from the twenty-year long experience of activity of a non-profit Italian organization that promotes a wide range of services and involves the resources of the community. A system including volunteers, public and private institutions, families, collaborators from different professional profiles has been progressively built from 1995 to this day, with three main goals:

- to help the person affected by Alzheimer’s disease (and other forms of dementia) and his/her family, both in developing an organized and functional care plan, both in react to the psychological distress
- to spread the awareness and the knowledge about dementia in the population, stimulating participation and involvement in the community members
- to compel a revision of the whole care system, through coordinating efforts among agencies.

Some data are presented about the composition of the system and on its effectiveness.

PO1.18. Developing a code of practice for dementia friendly communities

CAMPBELL Zoe

The Alzheimer’s Society is working with the British Standards Institution (BSI) on developing a code of practice for communities working towards becoming dementia friendly. This code of practice will provide guidance and ideas about:

- Who needs to be involved in setting up a dementia friendly community,
- Aims that should be central to all dementia friendly communities,
- Areas to focus on the processes needed for your dementia friendly community to operate successfully
- The positive changes for people with dementia we would expect to see from a dementia friendly community.

The aim of the code is to provide a framework, recommendations and some minimum standards for areas that are looking to become dementia-friendly and those communities that are part of the Alzheimer’s Society’s official scheme for recognising dementia friendly communities.
PO1.19. The influence of Alzheimer’s disease on family caregivers

STIGLIC Neza

Alzheimer’s disease (AD) is the most common cause of dementia and is defined as an irreversible, progressive brain disease. AD effects not only the person who is diagnosed but also brings challenges to those who assume caregiving responsibilities. In 2013, there were an estimated 44.4 million people with dementia worldwide and this number will increase to an estimated 75.6 million until 2050. Consequently each year there are more family caregivers who are facing a physically, emotionally, and financially demanding task.

The purpose of the research project was to investigate the influence AD has on family caregivers. Do they seek informational and instrumental support? Is taking care of a relative with AD a financial burden? Are there any differences between genders in their response to diagnose and are there any differences between partners and children of AD patients in capability of adjustments to new life conditions? Lastly we wanted to research what kind of environment do family caregivers design for patients and investigate signs of exhaustion that family caregivers suffer from.

Results show that effects on family caregivers are generally negative, AD loosens family bonds and relationships due to required high level of care. In most cases caregivers seek information and knowledge from health professionals and nursing-homes. Importantly women tend to react more active (seek informational and instrumental support) when facing diagnose of AD in family in comparison to men, who stay more passive. We did not found significant differences in capabilities to adjust to new living conditions between partners and children of patients AD. Moreover caregivers provide a safe environment for their relatives, but suffer from different signs of exhaustion, such as distress, irritability and anxiety.

We conclude that psychosocial interventions are advised to reduce caregivers’ burden. It is important that caregivers focus on their own needs and get support, both emotional and practical. There should also be more educational programs about Alzheimer’s disease and help groups for caregivers, so they could provide the best possible care for their relatives.

PO1.21. Pilot project in St Gillis commune (Brussels): How to do more with less public financial means for dementia

CLOSSON Marie-Christine, CAMMARATA R., DUFOUR Anouk, PRAET Jean-Philippe

To support dementia patients and their caregivers a lot of actors often intervene punctually, some without any expertise in dementia, in a crisis situation and are not well coordinated. This lack of coordination induces duplication of tasks (social and medical records…) without efficient return for the patient. A lot of models plaid for a special case coordinator. This solution creates problems: each actor (physicians, nurses, hospital…) will have the leading role in the coordination and will be paid for it in a context where no additional resources are available. That is why the St Gillis commune develops a continuous and long term strategy supported by the population:

• To forge pragmatic personal and professional links between the medical (general practitioners, nurses, pharmacists…), assistance (housekeeping,…) and social actors (social services, public services, older persons care services, cultural or other activities) working actually in the commune in order to better respond to the needs (medical needs, dependence, solitude, insecurity) encountered by elderly and their caregivers. Coordination in not a formal superstructure of institution or professionals but meetings or contacts between actors around the patient and their caregivers to find pragmatic solutions for each concrete problem.

• To develop population awareness of their capacity to be useful and to improve the human environment of dementia people and their caregivers: more attention and very little actions Social cohesion can allow dementia patient to stay alone and help caregivers. It will never be possible to finance on public resources all the needs for the continuity of care of dementia patient at home

Strategy includes several axes:

• ‘Destigmatisation’ of dementia patient: training and didactic folders

• “Alzheimer café” every month;

• Cognitive check-up within the geriatric service of the commune hospital (day care hospital) to identify the main problems to be able staying at home. Visit sat home of an occupational therapist and a social worker of the commune to discuss pragmatic solutions based on all the commune resources. Actually, the biggest problem is often that dementia people and their caregivers refuse progressive external help.

• Establishment of a volunteer service to help elderly in their everyday life;

• Establishment of an accompanying card for the older person in case of a problem

• To profit of the neighbour’s day to create contact with older persons.
Through the stories of 3 dementia patients living in the commune during the 10 last years (since the diagnostic to now), we will show how this organization and mobilization allow to manage pragmatic, human, respectful of the patient and their caregivers solutions along the different stage of the disease.

- Mister X: 60 year, with early dementia, very difficult social and financial situation, diabetic, blind. Exhausted wife refusing external help.
- Misses Y: 79 year with dementia, Spanish, alone, crises of paranoia, running away, naked
- Misses Z: 84 year, with dementia, violent with her husband, daughter living in France. Fusional couple without outside contact and refusing to enter in nursing home

This experience has proved that, much more then timely and heavy interventions, a long-term action, supported by population and all the medical and social actors of the commune is necessary to facilitate keeping at home old and/or dementia patients and to support the caregivers.

**PO1.22. Peterborough Dementia Resource Centre**

_DUNNERY Paul_

Launched in 2014 the Peterborough Dementia Resource Centre acts as a unique One Stop hub for People with Dementia and Carers to gain a diagnosis and access advice information and support to help them to live well with dementia. Anyone affected by dementia is able to drop into the centre and speak to an experienced member of staff. The range of services on offer at the centre include dementia support services, access to dementia advisors, information sessions, Singing for the Brain, Dementia cafés and training for carers. In addition, Alzheimer’s Society is working with key partners from the local health and social services sector, in order to deliver a wide range of holistic services, such as opticians, podiatrists and dentistry, hairdressers, and cookery classes.

The building is designed to be as dementia friendly as possible, with dedicated consultation and diagnosis space and an assessment environment designed with best possible outcomes for people attending.

We aim to promote choice to our clients and offer our one to one support in a variety of locations that best meets the client’s needs. Clients who accessed combined support report considerably higher outcomes than those who only accessed only one kind of support.

The Centre is centrally located within Peterborough City and is easily accessible. The building houses Consultants, a Community Mental Health team, a day centre facility and a not for profit café run by people with learning disability.

We see the DRC as the hub of community engagement and activities – promoting Dementia Friends and a local Dementia Action Alliance. The Centre has supported Peterborough achieve Dementia Friendly Community Status. The Centre is also reaching out to local communities and working with them to understand dementia and raise awareness and promote understanding.

**PO1.24. Possible explanations for and barriers to allocating and organizing support contacts for people with dementia:**

_A qualitative study with reports from administrators_

_JOHANNESEN Aud_

Background: Services to make society more inclusive or “dementia friendly” for people with dementia are needed. Support contacts can be one such service. Support contacts are “paid friends”. Their work tasks can be compared with respite care’ or volunteer work in other Western countries. Flexibility, adequate compensation, affiliation and satisfaction, together with potential for building relationship, are factors that stimulate support contacts in their work. The support contact service is rarely used in Norway and little is known why that is so. We therefore carried out present study based on reports from administrators in Norwegian local authorities.

_Aim_: To investigate administrators’ possible explanations and barriers to allocate and organize support contacts for people with dementia.

_Method_: The data was gathered from interviews with 35 informants, from 32 local authorities, during 2011. The analysis of data involved qualitative content analysis.

_Findings_: Three main categories emerged: knowledge, reaching out and management. Knowledge describes the administrator’s knowledge of dementia and of the law concerning offering people with dementia a support contact, and is described through two subcategories: formal knowledge and experiential knowledge. The category reaching out describes the circumstances leading families with dementia to apply for help and covers the subcategories supplying information about the service and characteristics of target group receiving a support contact. The category management describes the various ways in which the service may work satisfactory and contains the subcategories recruitment and organization.

_Consideration_: Support contacts are considered as a valuable service rated by the administrators. Furthermore, managers need to organize their departments so that administrators have sufficient knowledge about how to make the service available. In addition, support contacts must be given appropriate guidance and knowledge to maintain the service effectively.

**PO1.25. Improving the quality of life of people with dementia with targeted rehabilitation**

_GOMBOC Marjeta_

The decrease in physical activity is one of the earlier symptoms of dementia. Together with the consequences of aging leads to a decline in functional abilities of the individual. The result is a higher risk of falling and injuries. The deterioration of physical fitness and harder cooperation of the patient due to declining cognitive abilities are
PO1.26. Partnership between Bistrot Mémoire and cultural disposals

DONNIO Isabelle

The Bistrot Mémoire is born of the desire shared by both family caregivers and professionals to fight the stigmatization around dementia and work towards changing the societal perception of the condition. It is a place, a « café », « pub » (Bistrot), for people to share feelings, experiences and develop social ties between people with memory troubles, Alzheimer disease or assimilated forms and their family caregivers, one afternoon per week. Since we set up the first Bistrot Mémoire in Rennes, in January 2004, the concept, reproduced around 50 times in France, has been developed. We regularly introduced different supports to enable the citizens to reconsider their point of view about these troubles and to involve much more people with Alzheimer disease to take a real place in the community and participate, as citizens, to social life and cultural activities.

Our new project consists in creating partnerships with cultural and artistic structures, both linked with a “plateforme de répit”, one of the Alzheimer plan issue. The purpose is to give “good time shared” for both caregivers and people with dementia. For example, spending an afternoon at the museum, often a lost habit, by frighten, can become a new habit and a creative moment.

Thanks to the EFID workshop organized last year in Vienna, after the EFID award, we have been encouraged in our project in the way it contributes to change the image currently conveyed regarding Alzheimer’s and related conditions. We were invited to communicate differently on Alzheimer and similar diseases, with a slogan “I am still the same person”. And we tried together to bring much more nuance to the manner in which we communicate about these illnesses. We began by testing, with the participants, the opportunity to propose a first visit to the museum in discussing about “arts and emotions”.

As they enjoyed to get involved in the project, and spoke a lot about it in the meetings in Bistrot Mémoire, notably a man who talked about his difficulties to carry on with creative writing, we introduce with him the idea of a writing workshop, a time to make fun of words, to use “a word for another” or to experiment automatic writing as the surrealists.

Furthermore, we imagined to collaborate with dancers and choreographers in a project of choreography writing. Our priority is always to get and give pleasure with the proposal for both people with dementia and caregivers. And finally we are thinking about a film which would express, through these moments and experiences shared, the capacities that can be preserved, developed and enhanced in such moments and with such supports.

It is a moment of discovery that being ill does not impair feelings, that there is a lot going on inside each person, it is a time when each person is recognized positively, tenderly by the other ones… There are a lot of resources within each person: the Bistrot Mémoire enhances the expression of everybody, ill person or ken, and can contribute to illustrate the slogan “I’m still the same person”.

PO1.27. Ten years of experience for Bistrot Mémoire in France and a National Union to be representative and evaluate the concept

DONNIO Isabelle

The first Bistrot Mémoire in France is born of the desire shared by both family caregivers and professionals to fight the stigmatization around dementia and work towards changing the societal perception of the condition. It is a place, a « café », « pub » (Bistrot), for people to share feelings, experiences and develop social ties between people with memory troubles, Alzheimer disease or assimilated forms and their family caregivers, one afternoon per week. Since we set up the first Bistrot Mémoire in Rennes, in January 2004, the concept, reproduced around a hundred times in France, has been developed and also with different names as “Alzheimer cafés” or “respite café”. The initial project has entailed the drafting of basic principles, including ethical principles. Respecting one’s freedom of thought is the key word, whether he/she is a professional or a layman. Each new Bistrot Mémoire is supposed to create its own initiative in using...
These principles, in respect to the local projects and particularities. It's important for us to be reactive and to keep up the dynamic to contribute to the well being of both persons suffering from Alzheimer disease and caregivers. We regularly introduced different supports to enable the citizens to reconsider their point of view about these troubles and to involve much more people with Alzheimer disease to take a real place in the community and participate, as citizens, to social life and cultural activities.

Since 2006 we organised National Days of Bistrot Mémoire in order to share our experiences, the evolution of the concept in different territories, the difficulties to promote such new types of organisation which do not belong to classical social-care disposals but gives new conditions to welcome relations with people suffering from dementia and their caregivers. This way we evaluate our proposal and the different results observed in any place. Through the process of sharing our concerns, we have been growing all together. The large diffusion of the Bistrots Mémoire in France and in other countries (NL, UK, IT, AU) requires more research to gain a better understanding of their potential for socialization and participation of persons with dementia. The concept of “Bistrot Mémoire” has been first recognized by Foundations and Public Health Insurance, then by public administrations (city, department, region, state), and by the French Alzheimer Plan 2008-2012, particularly in several “plateforme de répit”, one of the Alzheimer plan issue, or in guidelines for promoters who have chosen to settle such initiatives or in different disposals as.

The National Union of Bistrot Mémoire has been found in 2009 in order to be much more representative and to have better recognition by all these institutions. Also, their role in fighting the stigma of the disease should be further investigated. The open access to persons with dementia without any previous assessment, their participation in “normal activities” with others, the opportunity to discuss and share ideas with others, can be seen as a way to stimulate inclusion and recognition. The Bistrots mémoire are set up in the west of France, and a national alliance was established with a website (www.bistrot-memoire.fr) in order to share, define preconditions and provide information about the Bistrot.

**PO1.28. Engaging the voice of family carers: the development of a dementia carers campaign network**

JOYCE Joanna, LEONARD Tina

In Ireland there are approximately 48,000 people living with dementia. Most of these people are cared for by a family member and there are approximately 50,000 dementia family carers. The Alzheimer Society of Ireland (ASI) is committed to ensuring that the voice of the person with dementia and the family carer is heard by the public and by policy makers. ASI facilitates the Irish Dementia Working Group and the Dementia Carers Campaign Network (DCCN). The DCCN is an opportunity for people who care for someone with dementia to meet and discuss issues which affect them and to campaign and lobby for change. This presentation will discuss the importance of supporting the voice of dementia family carers. It will trace the development of Ireland’s Dementia Carers Campaign Network, the first meeting of which was held in December 2013.

The presentation will reflect on the role national organisations can play in engaging the voice of family carers and lessons learned during the initial development of the DCCN. It will include examples of work undertaken by the DCCN, highlight issues that have arisen for family carers through their participation and set out the group’s plans for the future.

**PO1.29. About beliefs or why carers / volunteers need support, supervision and coaching**

ŠKRLJ Jože

People with disabilities (including people with dementia) should be looked at as subjects (with emotions and rights) rather than the objects (of medical treatment, social protection, physiological needs). If we focus on disease and symptoms rather than on persons, we fail to understand person-centred care. It begins with knowing the person and it requires the carer to recognise and value the person and treat him/her as an individual. Their biography, life experiences and the person’s actual needs as well as their beliefs, their likes and dislikes, even their fears should be taken into account. Therefore, it is essential that they are accepted as they are and not as we think they should be. Kate Swaffer said on her blog (http://kateswaffer.com): “Dementia care is caring for people who often do not know they need care, and don’t want to be in care; no wonder we may become angry and upset.” And many carers become angry and upset too. Although they are ‘trained’ to be good and effective ‘helpers’, they often perceive the wants, activities and reactions of the persons with dementia as ‘an attack’ on their competencies or on their willingness to help. The terms like ‘distressed reaction’, ‘behavioural disturbances’, ‘combative dementia’, ‘challenging behaviour’ are indicators of such conclusions. As our behaviour is led by our beliefs and expectations about the persons with dementia, we should be aware, that our reactions are (un)conscious part of caring, therefore, it is very important to recognize them.

Person-centred care for people with dementia has to be accompanied with caring of caregivers. Different types of support such as supervision, coaching and others (peer, expert, individual, group ...) should be essential for a professional approach of formal carers and also for effective care of informal carers, which enhance wellbeing of the persons with dementia.

**PO1.30. Carer involvement in cognitive-based interventions for people with dementia: a systematic review**

LEUNG Phuong, ORRELL Martin, ORGETA Vasiliki

Background: There has been increasing research interest in evaluating cognitive-based interventions (CBI) for people with dementia which comprise of cognitive stimulation (CS), cognitive rehabilitation
(CR) and cognitive training (CT) approaches. Given emphasis on the importance of ‘dyadic’ interventions, identifying whether these improve outcomes for people with dementia and their carers is important. The present review aims to systematically review current evidence base on carer-led cognitive based interventions for people with dementia and their effects on carer well-being and relationship functioning.

Methods: Systematic electronic databases were searched for randomised controlled trials (RCTs). Two reviewers worked independently to select trials, extract data and assess risk of bias for each of the studies meeting inclusion criteria, according to the criteria set by the Cochrane Review Group.

Results: A total 8 studies (n=938) dyads of people with dementia and family carers were included in this review. Four different levels of carer involvement were identified; 1) carers delivered the intervention, 2) carers delivered the intervention and received additional support by being provided with information about dementia and coping strategies, 3) carers were encouraged to repeat the cognitive-based activities at home with people with dementia and 4) carers were involved in repeating some activities at home and at the same time received psycho-educational support. Four studies examined quality of life outcomes for carers and most studies measured anxiety and depressive symptoms. Only two studies examined relationship functioning.

Preliminary analyses and pooling of the data indicate that carer-led cognitive-based interventions may be useful in improving carer well-being but further high quality studies are needed.

Conclusions: Our preliminary results show that limited data from two studies of carer-led CBI for people with dementia may enhance carer well-being. This review suggests that future carer involvement in CBI should be investigated by studies with sufficient sample sizes. It is important for future research to consider intervention duration and ‘dose’ of effect; as well as developing carer-led cognitive based interventions guided by interpersonal dementia caregiving theories.

PO1.31. Experiences and perspectives of people with dementia and their carers in taking part in a carer-led cognitive stimulation intervention: A qualitative study

LEUNG Phuong, ORRELL Martin, ORGETA Vasiliki

Background: Individual cognitive stimulation therapy (iCST) is a carer-led intervention for people with dementia. The iCST programme is a randomised controlled trial (RCT) that provides opportunities for people with dementia and their family carers to take part in a wide range of enjoyable and pleasant activities to stimulate thinking and general memory. The iCST programme is the first RCT to conduct an embedded qualitative study to explore the experiences and perspectives of people with dementia and family carers in taking part in a carer-led cognitive based intervention.

Methods: A sub-sample of 23 dyads of people with dementia and family carers who completed the carer-led cognitive based intervention took part in semi-structured in-depth interviews. Data was analysed using Framework Analysis.

Results: Major themes emerging from the data gathered were opportunities of being stimulated, being active in every-day life, ‘getting closer’, and understanding dementia in every-day life. The study findings suggested that taking part in the iCST programme provided general intellectual stimulation, helping people with dementia to ‘think better’ and increase their alertness and awareness. Some people with dementia and carers reported benefits of engaging enjoyable and pleasant activities which helped them to revisit or focus on new interests and hobbies. Many people with dementia and carers found that doing the activities together, provided opportunities to revisit ‘shared values’ enhancing mutual understanding and strengthening their relationship. It also provided carers with ‘awareness of the needs’ of their relative.

Conclusion: There are several limitations in this qualitative study such as a convenience sub-sampling. Most participants interviewed have done well with the intervention and data could have been affected by social desirability bias. This study provides further insight about the person with dementia perspective in engaging in home-based cognitive interventions led by carers. Some participants did not remember details of the activities but they were able to reflect on feelings of enjoyment. A considerable number of carers emphasised that iCST provided the frame for gaining a better understanding of the needs of the person with dementia, possibly by making carers more aware and sensitive to the person’s cognitive limitations.

PO1.33. Long-term and short-term predictors of worries about getting Alzheimer’s disease

CUTLER Stephen J., BRĂGARU Corina

Among older persons, Alzheimer’s disease (AD) generates higher levels of fear than any other disease. Concerns about cognitive functioning and worries about developing AD are also related to poorer health and lower psychological well-being. However, much remains to be learned about predictors of worries, concerns, and fear and especially from a long-term perspective. Thus, in addition to selected short-term effects, the principal objective of this research is to examine long-term effects of self-perceptions of cognitive functioning on current worries about developing AD. Data for the study come from the University of Michigan’s Health and Retirement Study. We use up to ten measurements of self-perceived cognitive functioning collected from 1992 to 2010 for respondents 50 years of age and older at the time of their entrance into the study. Demographics (marital status, age, education, and gender), beliefs about the role of genetics in AD, and personal knowledge of someone with AD are other variables included in the study. The data are analyzed using the full information maximum likelihood procedure within a structural equation modeling framework. The results show evidence of both long-term effects of cognitive self-assessment and short-term effects of beliefs and personal familiarity on worries about getting
AD. Specifically, a cumulative history of negative self-assessments of memory functioning, knowing someone with AD, and believing that being a first-degree relative of someone with AD increases one’s chances of having AD are all independently associated with higher levels of worry about getting AD. These findings reinforce the importance of examining cumulative subjective assessments of cognitive functioning as predictors of worries about developing AD. They also add to the body of information indicating that knowing someone with AD is associated with worries, and they point to the importance of beliefs and knowledge about the genetics of AD as predictors of worries.

**PO1.36. Dementia-friendly communication: a win-win for everybody**

CONSTANT Olivier

No dementia-friendly society without an emancipatory dementia-friendly communication. Only in this way, we can reach a global change of attitude. The roots of the still existing stigma on dementia start already with our shared visions on ‘dementia as a disease’ and ‘dementia as a caring process’. The consequence: negative perceptions that have an impact on the quality of life of all ages, not only elderly people. Therefore, there is an urgent need for innovative communication visions, strategies and methods. One thing is clear: if we want to involve all relevant stakeholders in a dementia-friendly community without barriers, we have to focus on added values and bottom-up strategies. Because of the impact of dementia-friendly communication on early diagnosis (as indicated during the first global WHO Conference on Dementia in March 2015), adequate training is needed. In this presentation, we combine the experiences of different small and large scale actions to break down the taboo concerning dementia in Belgium. Moreover, we learn from the latest conducted survey of the Flemish Expertise Centre on Dementia to measure perceptions on dementia across the country.

The goal: a transparent communication model that gives people with dementia and their caregivers the place they deserve: not in the margin, but at the center of a warm society. The key ingredients: a ‘tone of voice’ tailored to different groups, a layered and creative mix of media channels (online and offline), a proactive approach and the most important of all: the voice of people with dementia as a touchstone throughout the whole process. Inclusion, autonomy, permanent incentives and breaking down walls between health care and other policy areas are the essential basic conditions.

Everybody must dare to step into the world of people with dementia and learn from them. This takes time and patience, but the return for daily care practice and local policy will be priceless. Only if we dare to give meaning to the communication needs of people with dementia in every step of the process, we can really do justice to their dignity. The Belgian statistics are a call to action: the time is now to anchor the message of empowerment, across national borders. To conclude, we put our analysis in international perspective to clarify future learning points, challenges and opportunities. A cross-national dementia-friendly communication strategy is needed more than ever to preserve and intensify commitments made in all European countries.

**PO1.40. Sharing the journey: a pilot study in creating enriching relationships through expressive art**

BURNS Michelle

Art as a creative process enhances the lives of those living with dementia in many ways. It provides an avenue for expression, it becomes a therapeutic tool for evolving cognitive and physical abilities, and it offers an opportunity to build autonomy and independence.

Expressive art activities are an integral part of progressive dementia care but they can be challenging to execute successfully. Facilitators often observe anxiety, frustration and apathy, making it difficult to develop genuine connections. Over the past 8 years, I have developed an innovative expressive arts program to help address these issues in a non-pharmacological and often touching way.

As the Creative Director at Senior Access Adult Day Services in San Rafael, CA, I initiated a pilot study to test the hypothesis that caregivers can replicate this creative process to cultivate a deeper connection with people living with dementia. This method incorporates intentional steps that encourage interaction, helping caregivers experience spontaneous and striking moments that build meaningful rapport. Caregivers learn to recognize these moments as pivotal in the pursuit of dignified care.

The pilot study consists of a comprehensive workshop demonstrating the practical tools of this method. Caregivers participate in an instructional creative session as students and then facilitate their own creative sessions for individuals with dementia using these tools.

At this presentation I will share the outcomes of evaluations and reflections to determine what impact this method has on the caregiver’s ability to connect with the person living with dementia and the possibility of replicating this method in other care communities. This study embodies the ongoing effort to increase quality of life for people living with dementia, to honor their evolving place in society and to provide support for caregivers.

**PO1.42. Come to your senses – sensual architecture for people with cognitive risks**

DIETZ Birgit

As life expectancy continues to increase around the world, the need for new ideas on how to create an environment that is stimulating for all the senses is becoming more and more urgent. It is our senses that deliver us information on the state of our environment and our body’s position in relation to it. Every part of the body is involved in
PO1.43. Counseling Services Network for promoting dementia can reduce length of stay in hospitals, reduce falls and safe caretime. On top, we can reduce length of stay in hospitals, reduce falls and safe caretime. That process. Good design suitable for both, for the elderly and for people suffering from dementia can help to facilitate the processing of such sensory impressions and to minimize any misinterpretations. The presentation is based on different investigations in acute care hospitals and care homes. We introduce planning parameters which stimulate all senses and also offer safety and comfort. On top, we can reduce length of stay in hospitals, reduce falls and safe caretime.

PO1.43. Counseling Services Network for promoting dementia prevention and non-pharmacological interventions within public local authorities

SAKKA Paraskevi, EFTHYMIIOU Areti, LAVDAS Michalis, PANTEUJDOY Stella, MASTROGIANNAKIS Tasos,

There are 200,000 people living with dementia in Greece and around 400,000 family carers looking after them. Compared to existing needs, large areas of the country are not covered by any specialised service. Athens Association of Alzheimer’s Disease and Related Disorders (AAADRD) and Association for Regional Development and Mental Health (EPAPSY) in collaboration with municipalities in the metropolitan area of Athens and in Cyclades islands have developed a project for promoting dementia prevention and non-pharmacological interventions for people with dementia and their carers in the local community. The project is funded under the program “We are all citizens” by EEA and Norway grants. Bodossaki foundation is the National funds operator for Greece.

Since November 2014, 9 Dementia Counseling Centres have been established in Athens area and 4 in Cyclades islands. All Centres operate under the supervision of AAADRD and EPAPSY multidisciplinary health care professionals’ team.

The services provided are:

a) Dementia prevention: awareness campaigns, cognitive screening, cognitive training groups of healthy elderly
b) Interventions for people with dementia: diagnosis and follow-up, non-pharmacological interventions for people with Mild Cognitive Impairment and dementia
c) Interventions for carers: seminars, psychoeducational interventions, counseling services
d) Training of health care professionals already employed by the municipalities

AAADRD and EPAPSY are responsible for the service provision till the end of the project, April 2016. Health and Social Care Consultant, CMTprooptik will evaluate the quality of services provided by the Counseling Centres and disseminate results to all relevant stakeholders.

A core aim of the project is to develop guidelines for dementia counseling services in Municipalities in Greece. In this respect, we strongly believe that the health care professionals of the municipalities who have been evolved and collaborated with the implementation team, will continue the service provision to their local community after the end of the project.

PO1.44. The alzheimer café: an espresso with friends in adagio time

BARTORELLI Luisa, GIUBILEI Annalisa, BANCHETTI Serena, ARCANGELEI Francesca, CHERUBINI Laura, LEV1 Stephanie, RACNI Silvia

The Alzheimer café, born in Northern Europe, arrived in Italy in early 2000. The goal was to prevent isolation of people with Alzheimer’s and their families by giving them an opportunity to get together socially and to discuss their problems openly. Alzheimer Uniti has followed this philosophy choosing non-institutional meeting places that can accommodate people with Alzheimer’s disease. Alzheimer cafes, also called Memory cafes to avoid the impression of a therapeutic setting, however, still provide dignified “places of caring”, offering psychological support and information. They also promote social contacts and create networks of solidarity.

Material and Method: Alzheimer Uniti has opened and runs six Alzheimer cafes, which operate twice a month and are managed by a psychologist and a voluntary helper. Five of the cafes are in the city of Rome and the sixth is in the coastal town of Fiumicino. In honour of World Alzheimer Day in 2014, a new Memory cafe was inaugurated in the center of Rome, near the Parliament, and it is very popular thanks to the participation of invited guests (writers, actors, musicians, singers) who involve the people in activities. Alzheimer Uniti intends these cafes to be comfortable spaces, in a protected environment, where people with dementia can feel that they are the protagonist, have a voice and can avoid stigma. Cafes are attended by an average of 10 families and participants are normally people with a low to medium stage of dementia and their caregivers. A satisfaction questionnaire is distributed.

Results and Conclusion: By observing the evolution of the cafes over the past year one can see a gradual reduction of social isolation for the people with dementia and their families. The caregivers have said that this also leads to an easing of the burden of care. The Alzheimer cafe, under the supervision of experienced professionals in the field, is rightfully considered an informal service, part of the network. It is a form of social support where people feel considered and accepted in their fight against the loss of self-esteem. Also the caregivers feel accompanied along their difficult path.
back’ in the face of adversity. Resilience is therefore a ‘behavioural process’ built by strengthening personal attributes and external assets. However despite the recognized potential of resilience theory, the extent to which resilience exists or can be cultivated and nurtured in people with dementia is still relatively unknown.

**Aim:** This study explored people with dementias perceptions of resilience and the factors that facilitated or hindered their capacity to develop resilience.

**Methods:** A descriptive qualitative study was conducted based on the work of Thorne (2004). Semi structured interviews with a purposive sample of eight (n=8) persons with mild dementia were undertaken. The CORTE interviewing framework (Murphy et al 2014) was used to guide the interview process. This process maximizes the meaningful involvement of persons with dementia, ensuring that their voices are heard and to the fore. All interviews were tape recorded and transcribed verbatim. Transcripts were analyzed for themes and Windle’s (2012) resilience framework was used to guide the analysis. The criteria identified by Lincoln and Guba (1985) was used to ensure and maintain rigor.

**Findings:** Findings indicate that personal factors, enduring relationships, social support and community engagement matter to strengthening resilience. This small study concludes that people with dementia have the capacity to be resilient and building resilience matters for social inclusion.

**PO1.46. Living with dementia at home**

**KRIVEC David, KUNAVER Mojca**

Spominica - Alzheimer Slovenia with its 14 local branches was established in 1997. It is a non-governmental humanitarian organization, aimed at raising awareness and de-stigmatization of dementia and providing support to carers. Through our activities, volunteers of Spominica focus on meeting growing needs in this field in our society, especially among those affected by the disease and their carers. The main activities of our program “Living with dementia in dementia-friendly environment” are aimed at providing support, information and education to carers and family members of persons with dementia. Throughout Slovenia more than 5000 participants, mainly persons with dementia, their carers and professionals in the field, are involved in our activities.

In implementing our activities, we are seeing an increased demand for assistance at home from relatives of people with dementia. They require 24h assistance that is in most cases provided by their family members, which are faced with heavy physical, psychological, emotional and economic burden and are often faced with social exclusion and stigma.

For that reason, we have successfully applied for EEA and Norway grants with a project “Educational Program and Home Aid Group for People with Dementia”. The objective of the project is to contribute to the empowerment of groups of citizens suffering from dementia, to the recognition of signs of disease and facing illness, thus reducing the social exclusion of patients and their carers. With the project will transfer innovative good practice to Slovenia. We prepared a training program and a handbook for providing active home aid to the persons with dementia. We have launched a dedicated web site with useful information for carers. In addition to this, a pilot project with training workshops for caregivers and home aid group will be carried out. We plan to organize 4 workshops for volunteers who will act as home aid group.

**PO1.47. Dementia and rural housing**

**GRAY Patrick, HARRINGTON Paul, PASCOE Ann**

To show how a partnership has been established between the statutory sector as well as small and large partners from both the private and third sector such as housing associations, private landlords and local trades’ people to examine how local government, professionals and dementia friendly communities can work together to ensure people with dementia remain in their own homes for as long as possible.

How local communities were involved in raising awareness around rural housing issues i.e. that situations are constantly changing and often requiring urgent adjustments which cost money, but as importantly that ordinary families live in ordinary homes and that these homes are their family homes not institutions specifically for people with dementia.

How the rural partnership challenged existing preconceptions around rural housing by using local expertise to ascertain not only the existing rural situation and desires for the future, but also to show how communities could support government to ensure all local housing is dementia friendly.

And how a Rural Housing Charter can be developed for inclusion in a national Housing Charter.

How those ultimately responsible for funding and others who had authority to make change (generally from urban areas) were invited to a workshop to better understand how community connections and resources could aid in developing appropriate rural housing for dementia families.

How the work was intergenerational and socially inclusive i.e. how the students of the Glasgow School of Arts were invited to develop housing designs that incorporated not only dementia requirements, but also ensured any dementia friendly rural housing was also family friendly.

**PO1.48. Working effectively with people with dementia as Peer-researchers in qualitative research**

**DI LORITO Claudio, BIRT Linda, POLAND Fonna, CSIPKE Emese, ORRELL Martin**

Background: Peer-research, the involvement of People with Dementia (PwD) working as researchers alongside academics is a relatively new approach to Patient and Public Involvement (PPI) in research.

**Objective:** To report on the pragmatic realities of employing PwD as peer-researchers in projects using qualitative data collection methods and to appraise principles that can be used to assess the impact of...
PO1.49. Who am i?: an insight into the interpretations and needs for further research to understand how to effectively involve people with dementia

**Design:** We searched on PsychInfo and PubMed for specific articles about peer-research with PwD. Very few papers with a focus on PwD as peer-researchers were retrieved and therefore we broadened our focus and gathered information also from studies on peer-research with other service user groups (people with mental health problems, older people). To supplement published research with information on the practicalities of peer-research, we resorted to the toolkits published on the websites of organisations with a focus on health care and dementia such as the Alzheimer's Society.

**Results:** 11 studies were included in this review. One specifically addressed peer-research with PwD, two peer-research with older people, four peer-research with other service user populations and four focused on the general population of PwD. Results evidence that the process appears to generate a number of benefits for peer-researchers, academic researchers, participants and the research project as a whole.

**Conclusion:** This review, which is exploratory in nature, provides preliminary evidence that if risks are properly addressed and principles of good practice are applied, peer-research with PwD feasible and can generate a positive impact. Nonetheless, the extremely limited amount of research addressing peer-research with PwD and the lack of an established method to measure research outputs highlights the need for further research to understand how to effectively involve PwD as researchers.

PO1.50. Estimul'art: History, Art and Alzheimer

**Introduction:** This project has the goal to stimulate the memory and the cognitive capacities of Alzheimer's patients by means of the art and the historical memory.

**Objective:** To establish an ongoing relationship of activities between Fundació ACE, MFM and MUHBA.

To make it easier for people with Alzheimer's to have access to activities that are specifically designed for them. To carry out activities which improve memory and favor the reminiscence processes of the participants through the art and history, and material and immaterial heritage.

To evaluate the impact of these activities with the aim of understanding your impact on the cognitive and emotional development of the patients.

**Subject and methods:** The initial recipients of the program are 20 Alzheimer patients in mid or moderate stages of the disease, all of whom use SAD (Fundació' Daytime Care Services) and with a mid or medium-high socio-educative level. During the visits the staff from the Foundation will be there to accompany them as well as their families. The museums visits will be made in small groups and in alternate sessions. There will be a control group which will not visit the museums but will take part in the Fundació's work sessions.

**Results:** One aim of this project is to perform a qualitative evaluation of the activities and their effect on the people suffering with Alzheimer's and their caregivers. An evaluation would be able to show whether the effect is significant enough to improve their quality of life, or whether they are just leisure activities which take up their free time but do not result in any improvements.

In addition to a qualitative evaluation performed by those with Alzheimer's, the museum will also evaluate their activities. The result of the evaluation will help to future plans.

**Conclusions:** In progress.

PO1.51. Spouses of people with early-onset dementia.

**“Fundació ACE” groups’ experience.**

**Introduction:** One of the most important elements that influence on a caregivers well-being of a person with dementia is the social support. It is transmitted through the emotional support and practical assistance provided by natural social networks and social services. In this aspect, in the field of health, social, educative and therapeutic groups have been considered as an effective tool to complement the natural networks.

In assisting spouses of people with early-onset dementia, it was observed that those existing support groups, therefore, groups for people with late-onset dementia did not work; they used to give up...
PO1.52. The influence of day care centres for people with dementia on family caregivers: an integrative review of the literature

TRETTETEIG Signe, VATNE Solfrid, MORK ROKSTAD Anne Marie

Objective: Day care centres for people with dementia have received increased attention recently, due to a shift in policy from the use of residential care towards home-based services. The aim of this study is to provide an extended understanding of the influence of Day care centres on family caregivers.

Method: An integrative review including 19 studies was used: Qualitative (n=2), quantitative non-randomised (n=8), quantitative descriptive studies (n=7), and with mixed-method design (n=2). The quality of the studies was evaluated by the Mixed Methods Appraisal Tool (MMAT).

Results: Family caregivers experienced the Day care centres both as a respite service, and as support service, improving their competence in caring for the Person with dementia. Family Caregiver’s gender, role, individual needs, Person with dementia behavioural problems and need for assistance played an important role.

Conclusions: As a respite and support service, Day care centres have the potential to give Family caregivers a feeling of safety and relief, reduce the caregiver’s burden, and increase their motivation towards their role as caregivers. These outcomes depend on the quality of treatment, and how the service meets the Family caregiver’s needs for flexibility, support, information, and responsibility sharing.

PO1.53. Music and Dementia: A Conceptual Framework

GREASLEY-ADAMS Corinne, REYNISH Emma

In recent years there has been an increasing promotion of musical activities and singing groups for people with dementia. The power of music in the lives of people living with dementia is increasingly being observed through anecdotal reports, case studies and empirical research studies. Whilst the association between music and positive experience initially seems a simple one, our evidence-based framework highlights the complexities that underlie this phenomenon.

Our research sought the opinions of people who are working with, and/or have an interest in the role of music in shaping the experiences of people with dementia. A total of 106 respondents completed an online survey that asked open-ended questions about the impact of music and the mechanisms that might explain that impact and the challenges faced in facilitating music for and with people with dementia. Analysis of this data led to a draft conceptual framework being produced and being shared with 25 people at two working groups focusing on this topic. Feedback from these sessions was considered in the refinement of the conceptual framework.

We will present pictorially the conceptual framework that encapsulates holistically the various complexities that need to be borne in mind when thinking about the impact of music in the lives of people with dementia. The conceptual framework introduced highlights what people think might be happening and why, but also serves as a platform to inform the direction of future research and practice within this field.

PO1.55. Prostovoljska akcija univerzalne preventive pred demenco

HEBAR Karmen

V prispevku predstavljam namen, pripravo, izvedbo in evaluacijo akcije na temo univerzalne preventivne zasluge proti demenci z naslovom »Z aktivnostjo do kvalitetne starosti«, ki smo jo v okviru dijaškega prostovoljskega krožka ob Dnevu za spremembe izvedli na zavodu AMS.

Akcijo smo izvedli v obliki medgeneracijskega druženja, v katerem so sodelovali gimnazijarji, starostniki okoliških domov starostnikov, njihovi spremljevalci in mentorji prostovoljskega dela na gimnaziji. Z akcijo smo želeli udeležence ozaveščati o demenci ter o rizičnih in zaščitnih dejavnikih. Želeli smo jih spodbuditi k zdravemu stilu življenja (Na socialnem, mentalnem in telesnem področju), saj je slednji lahko zaščitni dejavnik pred demenco. Hkrati je bil namen akcije tudi spodbujanje mladih k prosocialnemu vedenju, k strpnosti in empatiji, k zmanjševanju morebitnih stereotipov in predstavnikov ter h gradnji posamezniku (z demenco) prijazne družbe.

Akcija je poleg ozaveščanja, izobraževanja in informiranja o demenci ter o rizičnih in zaščitnih dejavnih, zajemala konkretno aktivnost v delavnicah, ki lahko ob kontinuiranem izvajanju na daljši rok delujejo preventivno, pri blagoj obliki demence pa tudi kurativno. V delavnicah so udeleženci z družabnimi in didaktičnimi igrami urili socialne, motorične in orientacijske, vizualne, akustične in telesne
PO1.56. I want to be free

URH Miranda

Dementia brings considerable changes into someone’s life. It changes the life of the person with dementia, as well as relatives who at that moment may not realise they will not be able to face the disease. The distress and powerlessness of the relatives often results in placing the individual in a day care or an institutional care. Probably no one wishes to live like this, unable to take care of himself. The retirement homes, so it seems, are like a lifeboat, helping the relatives to survive the storm waters of emotion. Can this be changed?

Retirement homes in Slovenia are public and private. Those with a concession of Ministry of Labour are mostly private. The main difference is the price. Price-wise the private homes with concession in Slovenia could easily be compared to the prices of retirement homes abroad. Such retirement homes tend to be new and built according to the latest architectural standards. They have special care units for individuals with dementia since they require close monitoring and protection throughout the day. Retirement homes provide different forms of care for people over 65: day care, the centre for elderly, sheltered housing and home care. Persons with dementia entering a retirement home and their relatives can choose the service and make the transition less stressful. However, this depends on the vision, strategy and professional management of the retirement home.

I have decided to focus my research on 4 retirement homes (CS Cerknica, CS Zmzelen, DS Rive, DU Lidija) out of 99 total in Slovenia. My first impression was trough its communication (website, brochure.), later talking to the CEO, interviewing the head of the health care personnel within nursing homes, home care services and hospitals.

I decided to focus my research on retirement homes in Slovenia because of the concession of Ministry of Labour. The concession makes it possible to compare the prices of retirement homes abroad. Such retirement homes tend to be new and built according to the latest architectural standards. They have special care units for individuals with dementia since they require close monitoring and protection throughout the day. Retirement homes provide different forms of care for people over 65: day care, the centre for elderly, sheltered housing and home care. Persons with dementia entering a retirement home and their relatives can choose the service and make the transition less stressful. However, this depends on the vision, strategy and professional management of the retirement home.

PO2.1. Actifcare: Access to timely formal care

RØSBAEK Janne, VERHEY Frans, DEVUGT Marjolen, SELBAEK Gør, MEYER Gabriele, WOODS Bob, ORELL Martin, WIMO Anders, IRVING Kate, GONÇALVES-PEREIRA Manuel, ZANETTI Orazio

Background: Timely access to dementia care services is important for reducing health care cost by postponing nursing home placement, increasing quality of life for persons with dementia and reducing carer burden.
25th Alzheimer Europe Conference

Abstract Book / Posters

PO2.3  Finnish elder act - did it improve the legal rights of persons with dementia

MÄKI-PETÄJÄ-LEINONEN Anna, NIKUMAA Henna

The Finnish Act on the Care Services for Older Persons (the Elder Act) entered into force on 1 July 2013. The central objective of the act is to support the wellbeing, health, functional capacity and independent living of the older population and to improve their access to social and health care services of a high quality.

The act describes the content of the care chain for older persons and contains provisions concerning advice services, the mapping of the service needs, the right to have a service plan and the decision on granting social services. Furthermore, it contains regulations on the quality of services. The fact is however, that other legislation which applies to the population as whole, contain provisions that are very similar to the new act. One can thus ask, whether the act brought additional value for the care services for older persons and for persons with dementia. Did it, in fact, change anything?

Nevertheless, the Elder Act does contain some new regulations:

• An expert group (persons with dementia) is about to be established to give feedback and suggestions to RCG. It is important that the participants also find it meaningful to take part in this work.
• Involvement in educational where both parties are involved as lecturers in conferences, competence development and awareness raising programmes run by the other.

Results and conclusions:

• The contact between health care personnel/related municipal activities and people with dementia/interest organisation is strengthened. The themes, agenda and content in different programs have become more relevant.
• The interchange of information is enhanced.
• A user forum for people with dementia, led by the NHA-ODC, will function as an expert group for RCG.
• The health care personnel have strengthened their knowledge about the personal experiences of people with dementia and their carers.
• Relevant theory and experience is shared with the carers and people with dementia.
• The perspective of people with dementia and their carers is systematically included.

PO2.5  Successful implementation of national guidelines using modern technology

NORDBERG Gunilla, HOFFMAN Wilhelmina

The knowledgebase of dementia is under intense development at the same time as the care of persons with dementia face both opportunities and challenges. The Swedish Dementia Centre (SDC), established 2008, is a non-profit foundation and the Swedish national centre for excellence in dementia care. Our commission from the government is to collect, structure and disseminate knowledge and to facilitate translation of research and implementation of new knowledge into nursing and care. SDC actively promotes future development in care of persons with dementia – towards a more dementia friendly society.

Dementia ABC and Dementia ABC plus are seven web-based educations based on the national guidelines for dementia care, published 2010 by the National Board of Health and Welfare and best practices from experts all around Sweden. The educations were created by SDC to promote implementation of these guidelines. They also provides knowledge regarding The Swedish Dementia Registry, SveDem, a national quality registry on dementia disorders and the register for behavioural and psychological symptoms in dementia (BPSD).

Dementia ABC is the first basic step and Dementia ABC plus are tailor made for each specific level; Primary Health Care, Needs Assessors, Home-Help Services, Residential Settings, Hospitals and Relatives in order to cover the whole care chain. The aim of the educations is to follow the person from early stages until end of life. There is also a handbook connected to each specific target group that can be read separately but also act as a supplement.

The web-based educations are free of charge and accessible for everyone. After fulfilling a course and the participant successfully have passed the test, an individually numbered diploma is created. The educations are continuously followed up regarding statistics and can be followed on SDC’s homepage. More than 100 000 users are registered and new users are registered every week.

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PO2.6. Focus on dementia: supporting people to stay connected within their community

PEARSON James, PHILIPS Douglas, MILLER Michelle

The Focus on Dementia Programme is a partnership between Joint Improvement Team, Alzheimer Scotland and Scottish Government and Quality and Efficiency Support Team. An improvement collaborative approach is being undertaken to support health and social care partnerships in Scotland (rural and urban areas). Test sites are multidisciplinary teams working alongside people with dementia and their families and carers.

In the UK an estimated 40% of people with dementia live in some form of institutional care. This is higher than other countries. People with dementia and their carers do not always receive the range of health and social care interventions required to build their resilience and support them to live in the community.

A new ‘8 pillar’ model has been produced by Alzheimer Scotland alongside people with dementia and their carers and health and social care staff in Scotland. This evidence-based model is being tested in 5 health and social care partnerships. This model proposes a comprehensive integrated and coordinated approach to supporting people with dementia and their families and carers. This includes the introduction of a dementia practice co-ordinator function, a named, skilled, practitioner. They will ensure access to all pillars of support on an ongoing basis as appropriate to each individual, and will coordinate between all the practitioners delivering care, treatment and support. The other pillars include support for carers, personalised support, community connections, environment, mental health care and treatment, general health care and treatment and therapeutic interventions.

An improvement collaborative has been established nationally to support the 5 test sites to build capacity and capability for improvement, share data, progress, challenges and opportunities. A measurement framework and data reporting tool is in place for both qualitative and quantitative data reporting and analysis.

This work takes a therapeutic approach to enhancing the resilience of people with dementia and their families and carers: equipping and supporting them to cope with symptoms of moderate to severe dementia. The results of this work will inform the National Dementia Strategy for Scotland in 2016 and make recommendations about the adoption, spread and sustainability of this model. Lessons learned at the time of the event will be shared with delegates.

PO2.7. The use of real world data to tailor community services for persons with dementia and informal caregivers: The Bavarian Dementia Survey (BayDem)

SCHALLER Sandra, MARINOVA-SCHMIDT Velislava, SETZER Manuela, SCHNETZER Ina-Marlene, THRON Cornelia, POPP Susanne, HOESL Katharina, MASSICOT Gudrun, GASSMANN Karl-Günter, GRAESSEL Elmar, KOLOMINSKY-RABAS Peter

Background: The number of persons with Dementia in Bavaria (Germany) is predicted to increase from 220,000 (2014) to 270,000 in 2020. In average 70% are cared for at home, mainly by informal caregivers. Despite this situation, there is a lack of knowledge about the health care situation and individual needs of persons with dementia and their informal caregivers, which is especially true for rural areas. Therefore, the objective of the Bavarian Dementia Survey (BayDem) is to develop and improve treatment and care for persons with dementia and informal caregivers, by providing longitudinal information about individual care situations with a specific focus on rural areas.

Methods: BayDem is a multicenter project at three sites in Bavaria, Germany (Dachau, Erlangen, Kronach). Project participants are persons with a dementia diagnosis according to ICD-10 (F00-F03) and informal caregivers aged >18. To identify specific and longitudinal information about individual long-term needs and patterns in the care of persons with dementia, face-to-face interviews take place in close cooperation with local community institutions.

Results: To assess specific needs over the disease course, the following determinants are assessed in face-to-face interviews: Informal caregivers’ needs (CNA-D), resource use/uptake of community services (RUD), personal living situation, medical parameters, activities of daily living (ADCS-ADL), behavioural symptoms (NPI), caregiver burden (BSFC-s), and social networks (LSNS). Local project partners are: Hospitals (memory clinics), medical professionals (neurologists, psychiatrists, general practitioners) and community services (outpatient nursing services, caregiver counselling institutions).

Conclusion: BayDem will provide specific knowledge about Dementia treatment and care at three sites in Bavaria, by focusing on patterns of care and putting the person with dementia and their caregivers actively in the focus of research. The provided real word data results are of high importance for the development and improvement of local and national health and community services for persons with dementia and their informal caregivers.
PO2.8. The role of active caregivers and informal networks in supporting people with dementia

FABBO Andrea, PALESTINI Luigi, NICOLI Maria Augusta, LUDOVICO Livia

Being a person with dementia implies the need of a constant interaction with health care services: therefore, we need to focus on how such services can interact with active caregivers. Besides, people with dementia are also part of a community able to provide resources stemming from both primary social networks (family, friends, neighbourhood...) and secondary ones (local health care policies, authorities and organizations). Such resources could complement the activities of the health care services and avoid duplication of effort in support of people with dementia.

Our study aims on the one hand to trace the formal and informal networks of support for dementia, and on the other to investigate the psychosocial impact on caregivers for people with dementia. Caregivers are indeed central nodes in the aforementioned networks, but at the same time they are part of a community which provides resources to deal with the impact of a chronic and degenerative condition. In other words, the intersection of multiple support levels weaves the fabric by means of which a community absorbs the impact of dementia, and responds to the needs that it creates.

The study was carried out in two Emilia-Romagna Local Health Trusts by administering a questionnaire aimed at retracing caregivers’ formal and informal support networks, and at assessing a series of psychosocial variables that could be related to taking care of a person with dementia and accessing local resources for dementia support (i.e., caregiver empowerment, sense of community, caregiver perceived burden, perceived social support, perceived quality of life).

Data mining is in progress; preliminary results show that empowerment, burden, social support and quality of life levels are related to both socio-demographic variables (such as caregivers’ age, gender, employment status and education), and to the structure of networks the caregivers described (extension and composition).

PO2.9. “Support who supports”

SOMMELLA Francesca, MARANO Francesca, FRANCONE Caterina, De ROSA Giuliana, BRUNO Patrizia

Introduction: The association A.M.N.E.S.I.A., Italian acronym for Neurogeriatric Diseases and Alzheimer Syndrome Association, has promoted a formation course called “Support who supports”, to offer participants the best possible formation on the modalities of approaching dementia and the management of such clinical condition.

Purpose: The objective has been to guarantee a serene environment between operators and users through the teachings taken from the “Approach capacitante” developed by Dr Pietro Vignarelli, showing how the assimilation of such concepts can facilitate cohabitation with the users and succeed at instilling a valid help in the support to operators, frequently in burn-out conditions.

Materials and Methods: The formation course involved a group of 20 people, divided into Carers, Healthcare Assistants, Nurses, Psychologists and Social Workers who operate in the same Residential Care Home structure. An objective monitoring of burn-out indicators was carried out through the questionnaire on organisational welfare “O.Q.H.” by Avallone and Papolomatas (2002), handed out both before and after the course, by means of psychologists and educators. Moreover, through expressive and emotional group exercises, inspired to the technique of role playing, the operators were asked, as actors, to re-enact the relationship between the parties involved, with the aim to make the participants aware of their own attitudes towards imitation, action and the observation of the behaviour.

Results and Conclusions: The analysis of the questionnaire scores in the two conditions, has shown how the total scores significantly decreased in terms of the indicators of work ineffectiveness and psychophysical malaise. Moreover, the technique of role-play allowed participants to alienate themselves from their mental screens and to put themselves in the misunderstood reality of dementia. This allowed for greater sensitisation and better awareness in the way operators act and a more serene cohabitation for the user.

PO2.10. Attitudes of Hungarian family physicians regarding to screening and care of the Alzheimer’s disease

HEIM Szilvia, BUSA Csilla, CSERGO Agnes, KARADI Kazmer

The most common reason of major cognitive disorders (DSM-V) is Alzheimer’s disease, which worldwide causes a growing health, social and economic problems. In Hungary, it is also necessary to provide care for a growing number of elderly. Hungarian epidemiological data estimates about 200,000 patients with Alzheimer’s disease, however approx. 5000 patients are treated with specific therapy. The supply system has much of difficulties, only a few institution can provide high-quality care pathway. A large part of the burden presses on families and general medicine teams. The objective of recent study was screening how Hungarian family physicians think about the care pathway of people with Alzheimer’s disease.

We estimated 390 family physicians’ attitudes in relation to patients and their care system. A questionnaire survey was carried out among family physicians measuring above mentioned objectives. Descriptive analysis and non-parametric statistical tests were performed over questionnaire’s items. Most of family doctors felt regret, helplessness and uncertainty in relation to patients with Alzheimer’s disease. The knowledge of available diagnostic tools are reachable, but limited usage of them was reported. The family physicians considered therapy as difficult, challenging and requiring complex task. An important aspect is that nearly 80% of respondents did not take part in education related major cognitive disorders in the last 2 years. The WHO reports that the major cognitive disorders should be a priority in health care system in the coming decades. According to the gatekeeper function of family physicians their role is major and important in this process. A special attention should be given to their education and training in this field.
PO2.11. National data on social home help – organization and accessibility

LEBAR Lea, NAGODE Mateja

Social home help is a fundamental social care service provided at the home of the individual, but according to the planned scope, its development is significantly slow. The Social Protection Institute of the Republic of Slovenia every year monitors the implementation of social home help in every Slovenian municipality and therefore provides the national statistics and analysis in this field. Data from 2013 shows, that there is around 6,500 users of social home help in Slovenia, of whom 25 % have dementia. In the presentation, we will outline the most recent national data (as of 2014) with the special focus on organisation and accessibility of social home help. For a number of reasons, most common of which are geographical and financial ones, home help is not available to a number of potential users.

PO2.12. Do, enable, influence–Alzheimer’s Society UK translating research into practice

CAPPER Colin

Since 1990 Alzheimer’s Society UK has spent over £40 million on cutting edge research projects investigating the cause, cure, care and prevention of all types of dementia. As part of our care for today and cure for tomorrow research strategy by 2017 we will fund at least £10 million of new research each year, including new funding to support more research into practice initiatives. Over the years Alzheimer’s Society has received lots of feedback from members of our own workforce, people affected by dementia and the dementia research community indicating that more needs to be done to enable the findings from research to be taken up and put to use, particularly in the care setting. Put simply, we need to move beyond “more research is needed” to begin to see research translated into real world benefits for people affected by dementia.

In response Alzheimer’s Society has established a new team within its Research and Development Directorate working to fund and support research which:

- Brings together researchers and those who will put research findings into practice.
- Generates new knowledge in Implementation Science, developing understanding of what it takes to design, deliver and translate research into better outcomes for people with dementia in a range of settings.
- Identifies and supports the scaling-up of Implementation ready treatments, interventions and services from across Europe and evidence benefit for people affected by dementia.

This presentation will describe the Society’s journey to Research into Practice, highlighting what charity research funders can do to support research implementation at a European level, will explore some of the facilitators and barriers that can enable research implementation and the vital role played by people affected by dementia in influencing high quality research implementation. A number of case study examples will be used.

PO2.14. The cognitive impairment in a hyper-cognitive society.

BOADA Mercè, CANABATE Maria Pilar, MORENO Mariola, PRECKLER Silvia, ALEGRET Montserrat, HERNÁNDEZ Isabel, RUIZ Agustín, TÁRRAGA Lluis,

Introduction: Contemporary society has been qualified as a “Hyper-cognitive society”; a society based on knowledge, information and skillfulness to process data and to understand statements.

The pillar which supports it is knowledge in all of its models: discovered, still to be discovered, shared, available, understandable. Capacities needed to go through our current social environment necessarily rely on the skillfulness to interpret the load of information constantly deployed before. Reason (whatever technical, instrumental, theoretical, scientific or practical) is our time’s driving force.

Objectives: To analyze representations and practices generated by the cognitive impairment in a hyper-cognitive society.

Subjects and Methods: An ethnographic work was carried out throughout 8 years, combining participant and non-participant observations; 822 pieces of news and 2,123 documents issued by general practitioners to address patients to specialized diagnosis units were analyzed. Additionally, 30 in-depth interviews with people with dementia, their relatives and professionals working on dementia were collected.

Results: Losses related to dementia represent disintegration of the set of qualities which make up a competent individual. The use of “Alzheimer” term is tied to a constellation of meanings (loss, incapacity, dependency, overload, foolishness, decay...) which brings with it – and simultaneously restricts – certain trains of thought and courses of action. These meanings are recollected both in annihilating metaphors and in statements of institutions and individuals linked to the dementia, in family guides or in newspaper’s articles.

Conclusions: The representation of cognitive impairment tends to be hegemonic. It overlaps a sort of equally stigmatizing layers: non-autonomous, foolish, incompetent. Those categories convert cognitive impairment into a structure which holds different strategies aimed to marginalize, and by means of which one can justify the exclusion of individuals with dementia to the outskirts of society. This representation includes resistances which go far beyond ethics. New diagnoses in preclinical stages make that depersonalizing metaphorical descriptions be used reluctantly.

P03.1. RHAPSODY – Research to Assess Policies and Strategies for Dementia in the Young

JANSEN Sabine, DUBOIS Bruno, GAGE Heather, GRAFF Caroline, KURZ Alexander, De MENDONÇA Alexandre, SCHWERTEL Uta, De VUGT Marjolein E.

The frequency of Young Onset Dementia (YOD) is estimated at 100 per 100,000 in the population age between 45 and 65 years in Europe, Japan and the United States. There is a total of 16,000 affected individuals in France and United Kingdom and a total of 24,000 affected individuals in Germany. When dementia strikes at
PO3.2. Investigating the impact of volunteer mentoring on carers of people with dementia: a mixed methods study

SMITH Raymond, GREENWOOD Nan, DRENNAN Vari, MACKENZIE Ann

Background: Volunteer mentoring (befriending and peer support) is used across a wide range of services for people with varying needs (Casiday et al, 2009). Despite such schemes for carers of people with dementia (PWD) increasing in number (Department of Health, 2009), there is little evidence for the potential benefits they may offer (Smith & Greenwood, 2014). The aim of this mixed methods study is to investigate the impact of volunteer mentoring on carers’ mental health, loneliness and perceived social support using a mixed methods approach.

Methods: Nineteen family carers of PWD were recruited from schemes in Central and Southern England between February and October 2013. Carers completed the Hospital Anxiety and Depression Scale (HADS), the Multidimensional Scale of Perceived Social Support (MSPSS) and UCLA Loneliness Scale at baseline, 3 months and 6 months. Of the 16 carers who completed the quantitative phase, 8 took part in in-depth semi-structured interviews.

Results: Carers ranged in age from 34 to 85 years (average 63.6) and three-quarters were female (73.7%). No statistically significant differences were found for anxiety, depression or loneliness across the 3 time points. A significant difference in perceived social support scores was found (p = 0.042). Post-hoc analysis showed this to be between baseline and 3 months (p = 0.015). Of the 3 subscales of the MSPSS, only support from a significant other was shown to be statistically significant between baseline and 3 months (p = 0.013). Qualitative findings showed volunteer mentoring to be an important source of emotional and social support for carers, which was facilitated by the volunteers’ experiential similarity. Carers reported volunteer mentoring enables them to release emotional stress and to cope with challenging situations.

Conclusion: Volunteer mentoring offers carers emotional and social support which enables them to cope with challenges and continue caring. This has implications for potentially reducing the numbers of carers accessing statutory services and lengthening the amount of time PWD spend at home before entering nursing care.

PO3.3. More meaningful activities and better self-management thanks to the tablet? A person-centred programme that supports people with mild dementia and their carers

GRAFF Maud, KERKHOF Yvonne, De VOCHT Hilde, DROES Rose-Marie

Background: Because of the growing ageing population, eHealth services are stimulated to provide efficient and guaranteed quality of care. Due to this development, the availability of new applications (apps) in the field of health and social care increases. This also applies to the field of dementia care. To offer good support to people with dementia and their informal and formal carers in times of scarcity the deployment of the tablet is viable and desirable. However, at the moment it is not clear which apps are usable for supporting people with dementia and how these people can be coached to learn to use a tablet and its apps.

Research aim: Guidelines will be developed as part of a person-centred programme aimed at supporting people with mild dementia and their carers in how to use a tablet for meaningful activities and self-management.

Methods: The programme will be developed in accordance with the first phases of the Medical Research Council’s (MRC) framework for developing and evaluating complex interventions and covers the following phases: a preclinical or theoretical (0) phase, a modelling phase (I) and the exploratory trial phase (II). People with dementia and their carers will be involved during these phases, by means of individual interviews, focus groups and case studies.

Discussion: The iterative process of this framework makes it possible to develop a user-oriented intervention, in this case a person-centred programme for the use of tablets in dementia care. Preparatory work will be done to enable a methodologically sound randomised controlled trial (RCT), which aims to investigate the contribution of this person-centred programme for tablet use to the quality of life of people with dementia and their carers.
PO3.4. The meaningfulness of participating in support groups for informal caregivers of older adults with dementia: a qualitative systematic review

LALRITZEN Jette, PEDERSEN Preben Ulrich, SØRENSEN Erik Elgaard, BJERRUM Merete

Background: Support groups are considered an effective way to care for informal caregivers of older adults with dementia and relieve their feelings of stress and burden. Research shows, that participating in support groups seems to be beneficial for the informal caregivers, but with no significant improvements in feelings of stress and burden. It is unclear how support groups can produce a meaningful outcome for the informal caregivers.

Aim: To identify the meaningfulness of participating in support groups for informal caregivers of older adults with dementia living in their own home.

Method: A systematic literature review was conducted based on a peer-reviewed and published review protocol. 233 full-text papers were assessed for eligibility. Five qualitative papers were selected and assessed for methodological quality prior to inclusion using The Joanna Briggs Institute Qualitative Assessment and Review Instrument. Qualitative research data were extracted and the findings were pooled. This process involved the aggregation of findings to generate a set of statements that represent that aggregation, through assembling the findings rated according to their quality, and categorizing these findings based on similarity in meaning. These categories were subjected to a meta-synthesis that produced a comprehensive set of synthesized findings.

Result: The meta-synthesis produced three synthesized findings: 1. Emotional benefits of peer-based support, 2. Facing the challenges of caregiving, 3. Embracing the future through virtual configurations of group meetings

Conclusion: Peer support is meaningful and beneficial for informal caregivers. The support groups provide a source for obtaining positive emotional support, venting negative feeling and gaining help to deal with the everyday life of caring for older adults with dementia.

PO3.5 Stress, coping and service use: a qualitative exploration of the experiences of family caregivers

DOUGLAS Lorraine, POTTER Lauren, GOW Alan, MILDERS Maarten

Community-living people with dementia are often reliant on the support of informal caregivers, including spouses and other family members. Previous research has shown these informal caregivers to be at increased risk of negative outcomes such as stress and depression, and there have been many attempts at creating supportive interventions to help caregivers meet the challenges of caring for a person who has dementia.

The present qualitative study looks at the experiences of informal caregivers. Fifteen caregivers (including both spouses and children of a person with dementia) participated in semi-structured interviews, speaking about their experiences of caring for a family member who has dementia, the skills and resources they developed and used in taking on this role, their experiences of using community supports and their perceived on-going needs. Interpretative Phenomenological Analysis (IPA) was used to analyse the interview transcripts, with the primary aim of examining the experiences of informal caregivers. A secondary aim was to look at these experiences in relation to existing theories of caregiver stress and coping. Emerging themes from the analysis will be presented and related to existing knowledge about the needs of caregivers. Following on from this study, an intervention study is being carried out, focusing on the self-efficacy of informal caregivers in relation to certain aspects of caring for a person with dementia. The implications of the qualitative research for this and future intervention studies will be considered.

PO3.6. Digital Timelines project – using ICT to trigger memories

ŠKRLJ Jože

Digital Timelines is a two year (2014 – 2016) European Erasmus+ project that will create and pilot a training course and support materials to produce videos for the benefit of people with memory loss. The project aims to produce an effective resource which is at very little or no cost to the persons with dementia or their carers. The objectives of the project are to make maximum use of developments in ICT with regards “multi-media” digital devices to produce a training programme and digital resources to stimulate memory. It will benefit specifically the person with dementia and their family members, friends, volunteers, as well as professional carers. Within the project the partners will design a training package that is easily transferable and accessible to individuals, carers, family and professionals alike.

The training package will be cascaded on a one-to-one basis or in small groups. It will further be available as an eCourse, and will be supported by examples of digital timeline videos, as well as an instructional video, to ensure that along with many other complementary support interventions, the products are universally and freely available as open educational resources.

This nature of the project also addresses EU priority needs, including improving digital skills of adults and varying age groups in the care industry, encouraging use of open educational resources (OER) and providing open and flexible learning; including in practical application of ICT as an educational resource; a focus on the needs disadvantaged groups in society. Making the training resources available in Romanian, Slovenian, Turkish and Swedish addresses the need to produce OER in diverse European languages.

The project uses new ICT capacities to pull together and build on successful therapeutic initiatives already available. Slovenian partner is RESje team, which offers volunteer support to persons with dementia and their families, organized at ZDUS (Slovenian Federation of Pensioners’ Associations).
PO3.7. Data collection and evaluation in care for dementia patients in Czech Republic

VITECKOVÁ Slavka, KRUPICKA Radim, SZABO Zoltan, KUCKIR Martina, VANKOVA Hana, HOLMEROVA Iva

Geriatric conditions such as functional impairment and dementia are common and frequently unrecognized or inadequately addressed in older adults. Identifying geriatric conditions by performing a comprehensive geriatric assessment (CGA) can help clinicians manage these conditions. The aim of the paper is to present an effective method of data collection from CGA and its results using GDiag software. The results can then be quickly and efficiently shared across the provided services, therefore the individual care plans become effective both for dementia patients and service providers. Data collection (from the long-term care institutions in the Czech Republic) is currently performed generally in the form of paper questionnaires and then the data are manually processed. However, this method is not suitable from the viewpoint of bulk processing and long-term storage. Therefore, we developed a software suite GDiag for data collection and long-term storage which is designed to fit the needs of LTC providers. This suite consists of three tools: a questionnaire editor, a digitizing tool for printed questionnaires, and a web application for completion of the electronic questionnaires. The software suite is successfully used for monitoring parameters of patients with dementia in the Czech Republic, where individual long-term care institutions have collected data for two years. The results are currently evaluated and it is being published. This research project is supported by the grant NT11325 of the Ministry of Health of the Czech Republic: "Long-term care for seniors: quality of care in institutions, organisation ’s culture and support of frail older persons".

PO3.8. DemFACTS — Facts boxes for burdensome medical interventions in palliative care in dementia: a randomized controlled trial

LOIZEAU Andrea, EICHER Stefanie, RIESE Florian, MARTIN Mike

Introduction: Because of the impaired judgement that accompanies advanced dementia, decisions concerning burdensome medical interventions are frequently delegated to legally authorized representatives (mostly relatives). The ‘Facts Boxes’, developed in the US, are promising decision-making aids containing well understandable, evidence-based data about the nature, frequency and benefit of interventions. DemFACTS aims at the development of three ‘facts boxes’ for burdensome medical intervention in advanced dementia via participatory research. In addition, it seeks to assess the effectiveness of the facts boxes in terms of their ability to transfer knowledge, improve decision-making, as well as the general appropriateness of their content and format.

Method: The study has a cluster-randomized, controlled, pre-/post-intervention design. 250 nursing homes (cluster randomized) and SVBB groups (Swiss Association of Professional Health Care Proxies) in the German-speaking part of Switzerland will be asked for participation. Relatives of nursing home residents with advanced dementia (n = 200), professional health care proxies (n = 200), and long-term care nurses (n = 200) will make treatment decisions based on case vignettes. The intervention group will be presented with three facts boxes, while the passive control group will not receive any intervention. Several standardized and validated scales, e.g. Decision Conflict Scale (DCS), as well as items tailored to the purpose of the study will be used.

Expected outcomes: Primary outcomes are the post-pre increase in knowledge. Secondary outcomes are decisional content and the facts boxes’ effectiveness as decision aids.

Conclusion: This intervention is hypothesized to improve the decision-makers’ understanding of treatment decisions and their confidence in subsequent decisions. Improving knowledge transfer in palliative care decision-making could have a major impact on how decision-making aids in this field will be shaped in the future.

PO3.9. ABC Dementia – New ways of learning person-centered care for professional caregivers

TANNEBÆK Karen, REFSGAARD Elsebeth, GUNHILD Waldemar

Background: The Danish Dementia Research Centre has the task to disseminate knowledge and provide training for the professional caregivers in Denmark.

With the ABC Dementia we try new ways to offer training, and wanted to see if its useful for the professional caregivers in their daily practice.

Methods: ABC Dementia is a web based basic course for nursing and care staff. It consists of 10 modules with different themes. ABC Dementia translates evidence-based knowledge into best person-centered practice by using text, assignments, film clips, cases, virtual environments.

The web based course can be used alone, or it can be used in blended learning, where the user first completes the web based course and afterwards participates in a presence course.

Results: ABC Dementia was launched in may 2013 with the first modules, since it has been regularly supplemented with more modules. End March 2015 there were about 7300 users across the country. About 200 nursing and care staff had completed the blended learning course.

Conclusion: ABC Dementia offers flexibility as it can be accessed when needed. It gives the possibility for the user to practicing their approach, reflect and learn more about dementia.

It motivates professional caregivers to learn more about dementia and person-centered care, and it is a good add-on to other ways of spreading knowledge and initiating the dialogue, which is needed in order to provide good person-centered care for people with dementia.
PO3.11. Intellectual disability & dementia: Jenny’s diary

RITCHIE Louise, WATCHMAN Karen, TUFFREY-WIJNE Irene, QUINN Sam

People with intellectual disabilities are now enjoying a longer life expectancy than ever before as a result of enhanced medical and social interventions and improved quality of life. As a consequence of this we now know that some people with an intellectual disability, particularly individuals with Down syndrome, are susceptible to dementia at a significantly younger age. All dementia strategies in the UK state that everyone is entitled to know of their diagnosis, not only as a human rights issue but as part of developing appropriate and individualised post-diagnostic support. Currently there is limited guidance on how to explain dementia to someone with an intellectual disability, plus a shortage of information for friends, family and paid carers. This means that until information is shared about dementia, we are unable to position people with an intellectual disability as an authority on their condition.

Jenny’s Diary is a new free resource with an accompanying set of postcards (A5 size, full colour) funded by a Dissemination Grant from Alzheimer’s Society, UK. The postcards contain photographs of Jenny and other actors with an intellectual disability in a range of situations: domestic, community based or social. The images and accompanying easy-read text offer an explanation of changes in behavior with examples of how this information can be shared with Jenny, her partner and her friends. It forms a guide to support staff and family to answer questions and to develop a consistent, person-centred approach based on the specific need, cognition and understanding of the individual with dementia. This poster gives a pictorial guide to the development of this new and innovative resource, with examples of content.

PO3.12. Psychodemographic profile of non-professional caregivers of dementia patients in Poland, preliminary study

MOJS Ewa, SAMBORSKI Wlodzimierz, KRAWCZYK-WASIELEWSKA Agnieszka, MALAK Roksana

One of the most important changes in the care system is that due to increased life expectancy and the shift from acute to chronic diseases the number of disabled people has increased. Consequently, the number of individuals involved in caregiving, the duration of caregiving role and the types of caregiving tasks performed have also changed as for many caregivers such a role last for many years, even decades and caregiving has become very complex task.

The aim of the study is sociodemographic characteristics of non-professional caregivers of dementia persons in Poland. 50 caregivers of people with dementia participated in the study. They were recruited in Wielkopolska District. The mean of age was 60.7±14.20 in examined group. They were women mostly (73%). The results show that level of pain did not correlate with the level of depression. The caregivers have external support mainly from other relatives, they got institutional support occasionally.

The research supported by AAL fund. The title of the project: Understand a platform who help people with dementia

PO3.13. “I am living with and almost inside the music” – Music as a support in daily life activities for people with dementia and their caregivers illustrated by the example of Helga Rohra

WILLIG Simone

Music addresses people with dementia as human beings, not as patients. Music is life, is the living expression of life. Music facilitates an appreciative way of communicating, a dialogue amongst equals, in which the person with dementia can participate and shape his or her own experiences in a significant way. For a person with dementia, the experience of being appreciated and perceived as a person in the musical process, is often motivating and furthers and supports the person’s wellbeing, also in many areas of practical life. More than that music creates neural networks. Various musical parameters stimulate and link different areas in the brain at the same time. It has been proven that music activates centres in the brain that are responsible for emotions and instigates processes of neural reorganisation.

Music is always in interaction with motor control, executive functions, memory, language or attention. Illustrated by the example of Helga Rohra talking about music and how music therapy is supporting her participating in life, a large number of practical examples are provided and listeners are invited to participate and to discover music for themselves.


MJØRUD Marit, RØSVIK Janne, KRISTIANSEN Kari Midtbø, SELBÆK Geir

Aim: Person centered care (PCC) is found to be beneficial in patient care. The aim of this project is to increase knowledge and use of PCC and psychosocial interventions in community health care (long term care institutions and home services), to increase well-being in the patients and reduce use of coercive measures.

Method: The methods used for implementing PCC:
Marte Meo –use of film to explore challenging patient – staff interactions, feedback through supervision. Theory of Maria Aarts. Dementia care mapping (DCM) – observing patient – staff interactions, feedback through supervision. Theory of PCC, Tom Kitwood. VIPS practice model (VPM) – weekly consensus meetings to discuss challenging situations. Theory of PCC, Tom Kitwood, Dawn Broker, Janne Rasvåk. Structured non-pharmacological treatment – organizing/ routines in units, structured use of care plans. Theory of Gudmundsen. Subsidized courses in VPM, DCM and Marte Meo are offered to care staff with a minimum of bachelor-degree, who have teaching and /
or supervision as part of their work, working in old-age psychiatric wards, resource centers or centers for development of institutional and home care services. For the Structured non-pharmacological treatment model there is a book describing the method provided for units interested in using this method. The methods can be used independently or in combination. A project in long term care institutions where the methods will be combined starts in April 2015 and will be evaluated in October 2015.

Conclusion: It takes time to change care traditions in long term care, but there is a growing awareness in the community health care that there is a need of knowledge on PCC and a structure to help them achieve good patient care.

PO3.15. Innovative care – Psychosocial interventions
PRTENJAK Beti

The attitude towards people with dementia and appropriate environment are the two essentials that co-create a quality life of persons with dementia. For this reason we must pursue goals, based on a psychosocial concept of work with persons with dementia. Demographic changes in Slovenia and the needs of people with dementia require new forms of work concepts by putting them in the centre of attention. With the help of the appropriate staff – housewives – we create appropriate environment – household groups. With its architecture and a family-like environment, it encourages the person with dementia to be independence, safety and comfort. The kitchen as the centre of life appeals to the senses of people with dementia with all interactions and conversations. Architecture is ensuring privacy in single rooms. With their own equipment from home persons with dementia can turn it into a Home. Household groups operate on the principle of normalization. They offer traditional activities from their lives and allow autonomous decision-making. They create everyday life – all in connection to knowledge of the life stories of individuals. The concept is complemented by “the bathroom of well-being”. It is meant for encouraging the perception at the level of relationship with the person with disturbance in intellectual perception, especially among people with dementia and residents with less or no verbal communication possible.

With the introduction of palliative care we enable the relief of physical, spiritual and psychosocial ailments and advance planning. We provide permanent presence of relatives in the final stage of the disease in the room for palliative care.

But a quality foundation strives to act beyond by pursuit all efforts in the last two years focused on creating Šentjur a dementia-friendly place. That way it will be easier to confront dementia.

PO3.16. Caregiving in dementia: preliminary results on intervention on “person with dementia and caregiver dyad”
NEVIANI Francesca, FABBRO Andrea, MANNI Barbara, MONZANI Martina, SCARBI Cinzia, NERI Mirco, CHATTAT Rabih

Introduction: Many studies stressed the relevance of caregiver in the care of dementia, less is known on the effect of an intervention on both patient and caregiver. Aim: Ascertain the level of efficacy of a contemporary therapeutic approach (drug intervention for patient and psycho-educational for carer) on the dyad with respect to a control group.

Materials and Methods: A randomized case-control clinical study has been designed. A sample of 77 person with dementia (PWD) with MMSE ranging 12 to 27 with AchE-I treatment lasting 6 months to 2 yr have been selected. The presence of BPSD was also requested (NPI at least 1 item frequency x severity=> 6). Their carers have been contacted to explain aims and methods of the study and ask for participation, 24 decline the proposal. Then the carers were randomized in two arms (27 each arm), one for the psycho-educational intervention, the other for control. The intervention consisted on 4 one hour-sessions/month and a 3 months follow-up session. Three data gathering points were scheduled: T0 - T1 (1 month) - T2 (3 months). Main outcomes at T2= NPI and IADL/ADL scores; Carer= Caregiver:Coping:Orientation to Problems:Experienced (COPE); Secondary outcomes at T1 and T2: Patient= MMSE score ; Carer= Caregiver:Needs:Assessment for dementia = CNAD and Zarit:Burden:Inventory= ZBI .

Results: The study will end within 4 months, actual data refer to 48 To sessions (27 treatments an 21 controls) and 21 T1 treatment sessions. Socio-demographic characteristics: in both PWD and carers no differences were found between in treatment, control, refusal groups. Efficacy: at T1 a significant improvement in patient NPI score and carer CNAD-Problems subscore was found. For the latter, NPI-stress score and CNAD-Satisfaction subscore showed a significance level <10% > 5%. Correlations: At To in total sample and in the two sub-groups (treatment-control), patient NPI total score showed a significant correlation with NPI distress score and CNAD sub-scores of the carer.

Conclusions: The scores of patient behavior and carer perceived needs improved even after 1month treatment. This result is consistent with their strong correlation found at To and address towards positive results in main outcomes at T2.

PO3.17. Music as aid when caring for people with dementia
KAMMER Silke

You can reach people with dementia with music in a unique way. This is why music is often referred to as the royal road when working with people with dementia. Even short encounters with music are sufficient to awaken let alone increase i.a. attention. Music is neurophysiologically linked to emotion thus connected with memory.
Music possesses various possibilities to reach/contact people with dementia as nonverbal medium of communication and biological language of the brain. Moreover it plays a vital role in most people's life indifferent of them playing music themselves or being musical. It is important to work individually and in a person- and biography-oriented way!

You can avail of this person-oriented work when taking care of other people. People with dementia often times challenge caregivers in a special way especially at a later stage of the disease. Care can be eased via the ambient effect of music and its nature of awakening memory. Getting dressed will become easier with a song about fashion or clothing creating a new link. A lullaby eases going to bed for a person with dementia remembering him or her of their childhood calming them down. A jointly sung simple hiking song aids walking improving the gait pattern; making it more stable and more rhythmical and raising the feet higher and thus music prevents falling over. Singing helps preventing pneumonia due to the deep taking breaths and slow and even exhaling. With this knowledge, music can be integrated into care (for example in Germany AEDLs according to KROHWINKEL) and thus easing everyday life in care. The speech will demonstrate more examples and background. Moreover, it will explain the possibilities of interdisciplinary cooperation with music therapists.

**PO3.18. Music therapy as psychosocial intervention for people with dementia**

KAMMER Silke

You can reach people with dementia with music in a unique way. This is why music is often referred to as the royal road when working with people with dementia. Even short encounters with music are sufficient to awaken let alone increase i.a. attention. Music is neurophysiologically linked to emotion thus connected with memory. Music possesses various possibilities to contact people with dementia as nonverbal medium of communication and biological language of the brain. Moreover it plays a vital role in most people's life indifferent of them playing music themselves or being musical. Music therapy is completely unattached to musicality! Solely the music therapist must possess this skill in order to utilise the atmospheric effect of music correct and targeted. It is important to work individually and in a person- and biography-oriented way!

Scientific studies (RAGLIO et al. 2008) have found that symptoms such as agitation, anxiety and depression is reduced through music therapy. Moreover, self-confidence and willingness and ability to communicate are raised. Everyone who has had experience with singing or playing music with people with dementia will only confirm this. People become more attentive and feel that they are in good hands and understood. A lasting effect of music therapy is often described by caregivers or relatives that perceive people with dementia calmer and more communicative thus more balanced. This speech shall depict the mentioned effect and usage of music therapy as non-verbal psychotherapy for people with dementia and also discuss differences and similarities of the activity offer with music. Furthermore, the interdisciplinary possibilities of the cooperation between caregivers and other therapists will be pointed out.

**PO3.19. Dark shadows of dementia**

ZELZNIK Neva

Neva Zelznik. Two years after my mother died, I wrote a book about her vascular dementia. The title of the book is: Goodbye I’m going home ... and subtitle: Dark shadow of dementia. My book was the first one about dementia in Slovenia, written by someone with personal experience. In fact, it is a personal confession how I felt, and a lot of tips how to proceed on various occasions. Until then, the dementia was more or less taboo and stigma attached to the disease. Dementia is now much more known and I became the Vice-President of Alzheimer Slovenia. And why I wrote the book, which was sold out in two months? I am going to talk about that in my speech.

**PO3.20. Researching the wellbeing of people with dementia living in a purpose built care environment: Ways forward.**

BUSHELL Sophie, INNES Anthea, NYMAM Samuel

This paper will present my doctoral research using action research to implement activities to promote wellbeing for individuals with dementia living in a purpose built long-term care environment. The wellbeing of individuals living with dementia has increasingly become a topic of academic, professional and political discussion, along with a rise in research into interventions designed to promote wellbeing or quality of life amongst individuals living in care. However, existing research has overlooked the potential of the individual with dementia to make their own decisions regarding which activities may be most beneficial to their own wellbeing.

This research study proposes that the way forward in this area of research is to work in close collaboration with research participants, enabling them to design and choose their own activities for wellbeing. This approach is expected to produce better outcomes for wellbeing than traditional researcher-designed activities and to promote a more collaborative and inclusive approach to researching the lived experiences of people with dementia residing in care.

Within this research project, people with dementia are acknowledged to be the experts in their own lived experiences and are therefore in the best position to know which activities will benefit own wellbeing. The key then, is to enable people with dementia to express their preferences about activities and for care professionals to support and encourage engagement in these activities accordingly. This approach will use focused workshops to support people to design and choose their own activities and ethnography to evaluate the impact of those activities upon wellbeing. It is expected to produce better outcomes for wellbeing than traditional researcher-designed activities and to promote a more collaborative and inclusive approach to researching the lived experiences of people with dementia residing in care.
PO3.22. Psychosocial interventions

Lah Samira

Senescence of population has been a reason for dementia and it is growing fast. However, it does not affect only the affected individuals and their relatives but also wider society. With such intense growing manifestation, we think that prevention is of key importance. The studies, which have been researching risk factors for dementia, have been contradictory for several times. Nevertheless, numerous researches have shown that there important risk factors exist where we as individuals have influence to act preventively. The purpose of our article has been to focus on some preventive activities, which, according to our opinion, help lowering or decelerating risk factors for the development of the illness. The basic standpoint, which we stand up for with interventions, is to draw the therapeutic effects of individual activities through games closer, which connect different sorts of learning: social, emotional, mental, verbal, linguistic, sensitive motoric skills and orientation. All these are the areas, which are the most exposed in the process of illness’ progress.

In the article, we would like to present different didactic material and approaches which develop the individual’s areas. We have connected to the “gameteque” of Maribor library Nova vas which has more than 2000 didactic games. We would like to highlight the activities, connected with strengthening of the areas:

- orientation (chronological, spatial, personal);
- motoric functions and coordination of eye – hand (exercises for encouraging of balance, flexibility, manual dexterity);
- speech and language area, which are included in all other activities;
- sensual motoric exercises (we increase differentiation and recognition of sensual impressions);
- cognitive exercises (memory, attention, concentration);
- social skills (they help that an individual is active as long as he/she possibly can at the area of communication and socializing with other people);
- strengthen the healthy lifestyle and care for healthy diet.

With activities, we would like to offer the individuals a possibility for social connections among generations and lower the fear of the insecure future because we thing that it helps to build a friendlier and more tolerant society for people.


Gerritsen Debby, Van Vliet Deliane, Walravens Veerle, Koopmans Raymond

Background: Video Feedback at Home (VFH) aims to improve the well-being of the informal caregiver and the person with dementia (PWD) by training the caregiver to communicate successfully. There is hardly any scientific evidence for VFH.

Objectives: The aim of this pilot was to investigate if VFH has an effect on the quality of the interaction between PWD and informal caregiver; affect and experienced burden of the caregiver; and the number and intensity of PWD’s challenging behavior. A second objective was to perform a process evaluation focusing on barriers and facilitators regarding the use of video in interventions.

Methods: 25 VFH-cases were to be studied in a pre-post design. A rating schedule was developed to rate video footage on quality of interaction. Affect and burden were measured by the Positive and Negative Affect Scale and the Short Sense of Competence Questionnaire. Challenging behavior was measured using the Cohen-Mansfield Agitation Inventory. Additionally, semi-structured interviews with caregivers were administered. For the process evaluation participating caregivers were interviewed and a questionnaire was administered to declining caregivers, stakeholders and field experts concerning their views regarding VFH.

Results: Ten couples participated in the pilot study. When the rating of the video footage was specified according to each individual VFH trajectory, improved quality of the interaction was observed in half of the cases. Scores on most questionnaires improved. In the process-evaluation various barriers to VFH were mentioned, most importantly a psychological threshold for caregivers and lack of familiarity with VFH among caregivers and referrers.

Conclusion: Although VFH could be an effective intervention, the current barriers to its use are very high. The results provide practical implementation guidelines to possibly overcome these barriers. Further, our study can guide future studies on interventions using video and more generally interventions using technology in dementia care.

PO3.24. Dementia and sensory challenges

Houston Donna, Houston Agnes, Gray Patrick, Pascoe Ann

To show how a project instigated by Agnes Houston, a person with dementia, found that regardless of a dementia diagnosis, sensory issues were not being dealt with despite being a lived experience by many and how in partnership with a dementia friendly community she gave hope to people affected by dementia on how to live a positive life with sensory issues.

How the project enabled people with dementia, their families and carers plus professionals to be better equipped to deal with sensory problems around vision, hearing, taste, smell and hallucinations. How narratives were collected from people with dementia experiencing a range of such sensory problems. How the information from these interviews was examined and transformed into a practical leaflet outlining the issues together with hints and tips.

How direct outcomes confirmed for both people affected by dementia and professionals that:

- dementia is more than memory with definite signals pointing to sensory issues
- sensory issues are very common and that most people with
PO3.25. Unmet needs of community-dwelling people with dementia in primary care and the benefit of a formal dementia diagnosis

THYRIAN Jochen René, EICHLER Tilly, HERTEL Johannes, RICHTER Steffen, WUCHERER Diana, MICHALOWSKY Bernhard, TEIPEL Stefan, KILIMANN Ingo, DREIER Adina, HOFFMANN Wolfgang

Objectives: To provide optimal care for people with dementia, the individual unmet needs have to be identified and comprehensively addressed. Main objectives are (1) to describe the number and types of unmet needs of community-dwelling primary care patients in Germany screened positive for dementia and (2) to examine whether formally diagnosed patients have less unmet needs than undiagnosed patients.

Methods: DelpHi-MV (Dementia: life- and person-centered help in Mecklenburg-Western Pomerania) is an on-going general practitioner-based, randomized controlled intervention trial. The present analyses are based on the baseline data of 180 patients of the intervention group with completed standardized, computer-assisted needs assessment until October 7th, 2014 (preliminary data).

Results: (1) Patients screened positive for dementia had on average 8.2±4.5 unmet needs. The majority of unmet needs occurred in the action fields “nursing treatment and care”, “social counselling and legal support”, and “pharmaceutical treatment and care”. (2) Formally diagnosed patients had significantly less unmet needs than patients without diagnosis (7.4±4.0 vs. 8.6±4.6), independently of age, sex, living situation, cognitive impairment, functional status, and depression.

Conclusions: The results emphasize the importance of a comprehensive needs assessment that allows the identification of unmet needs as the basis for a tailored intervention plan. Patients seem to benefit from the presence of a formal diagnosis. However, the number of unmet needs in formally diagnosed patients was still high. The presence of a formal dementia diagnosis is not sufficient to ensure optimal treatment and care; further measures – such as Dementia Care Management – need to be taken.


DUNNERY Paul

In rural areas of Northern Ireland where people with dementia and there carers are affected by high levels of isolation the Alzheimer's Society offers one support worker to be available from when the person is diagnosed, through review clinics, at community support, 1:1 support and carers information programmes and peer support group. The benefits of one support worker enable the person with dementia and the family not to have to repeat their personal story at each stage and group they attend, the SW can ensure that the service is a bespoke as possible to them and reduce stress for the family and PWD.

This is a particularly beneficial in rural communities where people still live in close proximity to lifelong neighbours and family and can be unaccustomed to meeting and sharing personal history with outsiders compared to those who live in more transient communities.

PO3.27. Small group living for persons with dementia – is there a difference to traditional care?

ALER Stefanie, CECK Monika, KIENBERGER Ursula, HOFMANN Bettina, VIÉRECKL Carmen, WIMMER Sonja, SPAN Edith

Background: Care Models supporting Persons with Dementia in institutions are currently changing in many countries. There is a development towards “person centered” and “stage specific” care. Smaller care homes or “group living” concepts are thought to be advantageous because they provide care in a homelike rather than an institutional milieu. Despite the face validity of smaller institutions, there is little evidence in favor of these concepts available.

Methods: We report on a one year longitudinal observational study involving persons with dementia residing in a group living model and in traditional care settings, care team members and relatives. Persons with dementia participating in the study were matched with respect to sex, age, dementia severity and number of medical diagnosis. All persons were assessed at baseline, 3 months and 6 months. An additional 6 months observational phase was set up. As primary outcomes Quality of life (QUOL-AD, person with dementia version) for the person with dementia, work satisfaction for care team members and Quality of life (family version) for relatives was chosen.

Results: 36 Persons (28 female, 8 male) with Dementia (10 persons living in a group living, 11 persons in a traditional and 15 persons in a semi-traditional environment) in different stages of the disease participated in the study (mean MMSE 16.5, SD=6.3). There were no significant differences on any of the main outcome measures observed.

Conclusion: This study did not find significant differences on the main outcome measures between the different care concepts suggesting that milieu may not be the main factor of quality care.
PO3.28. Professional Care Team Burden Scale (PCTB)
AUER Stefanie, GRAESSEL Elmar, VIERECKL Carmen, KIENBERGER Ursula, SPAN Edith

Background: There are high expectations put on institutional care according to the principles of “person centered care” and the related skills of understanding the needs of persons with dementia beyond regular “physical care” resulting in a high emotional investment on the side of the care teams. This situation can create considerable burden, maybe comparable with the burden experienced by family caregivers. There are very few dementia specific assessment instruments available to assess burden in care teams.

Methods: On the basis of the theoretical concept of subjective, objective and structural sources of burden, an item pool consisting of 40 items was constructed based on interviews with care team members. 3 experts selected 19 items in a consensual process. The perceived Stress Scale (PSS) was chosen as a criterion in order to test discriminant validity.

Results: 172 persons participated in the scale construction study. The stepwise scale analysis revealed a 10 item scale solution. The Cronbach’s alpha was 0.78. The Pearson correlation between the PCTB scale and the PSS was 0.46 (p<0.001). All included items could clearly be assigned to one of three factors.

Conclusion: The 10 item PCTB scale provides a valid and reliable means of obtaining ratings of burden from formal care teams working in nursing homes in order to evaluate different interventions targeted at the reduction of burden in care teams.

PO3.29. Improving care for people with dementia/delirium within acute care settings
McALISTER Janice, COPELAND Claire, MACHAROUTHU Ajay

Improving care for older people and support for those with a diagnosis of dementia/delirium is a priority for NHS and as such, integrated working between specialist services has provided the opportunity to imbed an expansive training programme based on the principles of “Promoting Excellence: Through integrated working a need for training in dementia/delirium care was identified by staff within the Acute Hospital sector. To meet this identified need a variety of training programmes and care pathways have been developed and imbedded into practice.

During training sessions a substantial amount of time is spent exploring the appropriate use of non-pharmacological interventions in the care of patients with dementia/delirium within general hospitals, this includes the use of Cognitive Stimulation Therapy, Psychomotor Therapy and Multi-Sensory Therapy. During these sessions, it has been highlighted by staff how eager they are to introduce an array of person centred proactive treatments against a backdrop of reactionary care management. Integrated person centred care pathways for Dementia/Delirium have now been developed and imbedded into practice within general hospital sites.

This initiative has at it’s core the vision of Rights, Relationship & Recovery in breaking down traditional organisational/professional boundaries with the aim of driving forward service improvement for patients with dementia that is person centred and strengths based.

It has brought about partnership working with a common goal of positive change in practice in dementia/delirium care within acute hospitals.

This programme of change was developed to drive forward Scotland’s Dementia Strategy, Promoting Excellence and Standards of Care for Dementia in increasing staff’s skills and knowledge at all levels and ensuring patients have carers who are educated and supported in dementia/delirium care.

The theme throughout the change programme is person-centred care which is non-discriminatory, focusing on individuality and uniqueness of patients who have a right to care and treatment regardless of diagnosis.

PO3.31. Multi-sensor analysis and decision making for supporting people with dementia
MEDITSKOS Georgos, STAVROPOULOS Athanasios, KOMPATSIARI Ioannis

Ambient Assisted Living (AAL) is one of the leading technological paradigms of the future, building upon the visions of Pervasive and Ubiquitous Computing. AAL specifically targets Quality of Life and eHealth for the elderly, disabled or people who need medical attention in general. This work presents the fundamental, underlying technologies of the DemaWare platform, which provides novel solutions for the holistic management of dementia, based on both medical knowledge and the latest advances in pervasive computing and sensor technologies. To this end, DemaWare delivers a multi-parametric monitoring framework that sustains context-aware, personalized and adaptive feedback mechanisms for the remote management of people with dementia. These include, physiological and lifestyle sensors, object motion, electric, presence and environmental, as well as wearable and ambient cameras and microphones. Through intelligent fusion and context-aware aggregation of the different types of knowledge, DemaWare provides personalized feedback and care management services, coupling clinical and domain knowledge with profile contextual history and care plans. This is achieved through reasoning techniques and decision making procedures that effectively integrate, link and correlate the information to support the monitoring of discern traits that have been identified by the clinicians as relevant for assessment and diagnosis, aiding them to design and adjust interventions. In addition, the platform offers a multitude of tailored user interfaces suitable for caregivers and clinicians, enabling them to monitor and assess a person via aggregated or detailed daily activities, physical activity, sleep and abnormal situations or behaviors, e.g. abnormal sleep trends.
PO3.34. Developing dementia support in acute care settings

McNAMARA George, SMITH Kathryn

The Alzheimer’s Society is pleased to present for consideration, a pioneering pilot project aimed at improving the hospital stay for people with living with dementia and their carers. The evidence supporting this work is compelling. 25% of hospital beds are used by people with dementia at any one time. People with dementia are likely to spend three weeks longer in hospital than people without dementia admitted for the same procedure, and the majority of those with dementia will often deteriorate as a result of their hospital stay. With the number of people with dementia set to rise to over 1.4 million in the next 30 years, this pilot is an attempt to bridge a gap in the current support provision for patients admitted into hospital with dementia and their carers. Designed to complement hospital care, this specialist service recognises the difficulties patients with dementia may face during hospital stays, regardless of their reasons for admission.

Over the two years of the pilot, the project has built on the very limited support available in hospitals for people with dementia and their carers by offering a high quality, innovative service. Working in partnership with the two hospitals involved, small but dedicated teams provide person-centred support during a stay and beyond, ensuring vital, continuity of care by referring back into community support services. This vital work results in invaluable information and guidance from the point of planned or emergency admission, right through until discharge. It is designed to enable patients and their carers to understand and cope better with their time in hospital. This improves their chance of being discharged from hospital sooner and with the support they and their carer need to continue to live well in their community. This reduces stress and ultimately reduces the cost of keeping people in hospital longer than necessary.

PO3.38. Brain fitness – One-to-one tailor-made exercises for people with dementia and their carers

LAMBERCAR Jasmina

Brain Fitness comprises of memory and attention exercises, memory and relaxation techniques, which have a positive effect not only on helping people with dementia retain their memory capacity longer, but also prove beneficial to their creativity, meaningful communication and well-being. This particular combination of different techniques and exercises also serves to prevent pathological loss of memory and has positive results on health and well-being of family members and carers.

Brain Fitness is based on a person-to-person approach. In working with a person with dementia, a memory trainer is aware of her/his life story, cultural background, significant events and significant others. This information is used to design a tailor-made program for each individual person. This makes the activity useful, pleasant and sensible. The exercises are designed on basis of individual client’s life story and his/her psychological and physical characteristics. The activities consist of:

- attention exercises (using sense organs (hearing, smell, touch, sight, taste) and emotions e.g. anger, fear, joy);
- short term memory exercises to improve storage and recall of information (memorizing words, numbers, lists, faces and names);
- long term memory exercises (organizing, structuring and connecting information);
- memory techniques, a simple tool to storing, connecting and recalling information;
- relaxation techniques and balance exercises (walking, standing, sitting).

PO3.40. Advance care planning in residential care settings for older people in Italy: knowledge, attitudes and experience of healthcare professionals.

MARIANI Elena, CHATTAT Rabih, VERNOOIJ-DASSEN Myra, ENGELS Yvonne, INGRAVALLO Francesca

Background. Advance care planning (ACP) has demonstrated to improve end of life care and satisfaction of elderly patients and of their family carers, reducing symptoms of anxiety, depression and stress. In Italy legislation about advance directives is still lacking, and there are no data available on the use of ACP in clinical practice.

Objective. To investigate healthcare professionals’ (HCPs) knowledge, attitudes and experience with ACP in the context of residential care settings for older people in Italy.

Methods. A 54 item questionnaire was administered to all HCPs (n=306) of 11 Italian residential care facilities.

Results. One hundred and sixty five of HCPs (54%) completed the study. Only 28% of HCPs answered the section of the questionnaire on ACP knowledge. The questions with the highest rate of uncorrected responses were those regarding whether ACP is a legal document (88%) and that it can only be done by doctors (42%). Overall 82% of respondents favour the use of ACP. The main barriers to ACP appear to be the lack of skills to discuss it (28%), and the perception that both patients and HCPs are not prepared to discuss ACP (26 and 27% respectively). The fear that ACP may upset relatives (35%) and patients (29%) was the main concern of HCPs. The most frequently perceived benefits of ACP are: to allow patients to have sense of control over their lives (73%), to be able to influence their future treatment in case they lose competence (69%) and to decrease burden of decision making on family (69%). Forty nine per cent and 83% of HCPs does not know whether ACP discussion is part of their role and does not discuss ACP (88%) and that it can only be done by doctors (42%). Overall 82% of respondents favour the use of ACP. The main barriers to ACP appear to be the lack of skills to discuss it (28%), and the perception that both patients and HCPs are not prepared to discuss ACP (26 and 27% respectively). The fear that ACP may upset relatives (35%) and patients (29%) was the main concern of HCPs. The most frequently perceived benefits of ACP are: to allow patients to have sense of control over their lives (73%), to be able to influence their future treatment in case they lose competence (69%) and to decrease burden of decision making on family (69%). Forty nine per cent and 83% of HCPs does not know whether ACP discussion is part of their role and does not discuss ACP (88%) and that it can only be done by doctors (42%). Overall 82% of respondents favour the use of ACP.

Conclusions: These preliminary data show that most of HCPs working with elders in residential settings favour the use of ACP and acknowledge its role in promoting patient’s autonomy. However, only few of HCPs discuss ACP, usually on request of patients and/or their caregivers. This result may be related to the fear that ACP may upset them.
PO3.41. Palliative care and symptoms of discomfort in hospice patients with and without cognitive impairment
Van Der ROEST Henriëtte, WOUTERS Nadia

Background and objective: There is uncertainty whether palliative care for people with and without cognitive impairment is provided according to their needs. The first objective of this study is to examine and compare the symptoms of discomfort and types of provided palliative care to hospice patients with moderate to severe cognitive impairment (moderate/severe CI) and patients with no to mild cognitive impairment (no/mild CI). The second objective of this study is to examine the relationship between symptoms of discomfort and types of palliative care provided.

Method: 66 terminal patients admitted to a hospice were included in the study. Most patients had a primary diagnosis of cancer. Data were collected between September 2006 and December 2007 by trained hospice staff with the Resident Assessment Instrument – Palliative Care (interRAI-PC). Cognitive impairment was determined by means of the Cognitive Performance Score (CPS): Twenty patients (30.3%) had CPS ≥ 3, indicating moderate/severe CI. Variables from the interRAI-PC were used to describe and compare symptoms of discomfort and types of palliative care as well as the relationship between them.

Conclusion: No differences with regard to age and gender were found between hospice patients with no/mild and moderate/severe CI. Hospice patients dying from a terminal illness (mostly cancer) with severe/moderate CI have probably more symptoms of discomfort, and receive with regard to hallucinations (bladder and bowel) incontinence and fall incidents suboptimal palliative care as compared to terminal care patients with no/mild CI. Management and educational strategies are needed to improve end-of-life care in patients with severe cognitive impairment.

PO3.42. Dementia Ambient Care: A holistic approach to the management of dementia in multiple care settings
HOPPER Louise, JOYCE Rachael, MELANDER Catharina, KIKHIA Basel, KARAKOSTAS Anastasios, SÄVENSTEDT Stefan, IRVING Kate

Assistive technologies that continuously monitor the person with dementia’s behavioural, cognitive, and emotional state facilitate more objective means of assessing, monitoring, and supporting the individual than that provided by traditional questionnaires. The “Dementia Ambient Care” (Dem@Care) EU-FP7-funded project investigated the use of multiple wearable (actigraphy, 2D/3D cameras, microphones) and ambient (visual and infrared cameras, sleep) sensors for the recording of daily activities, lifestyle patterns, emotions, and speech, to develop a novel approach to the holistic management of dementia, in multiple care settings. This paper presents findings from the use of Dem@Care for remote monitoring and support in the home of the person with mild dementia, and for the clinical assessment and management of Behavioural and Psychological Symptoms of Dementia (BPSD) for people in more advanced stages in a residential care setting. Four ‘home’ participant cases will be discussed; two in Greece and two in Ireland. An intervention study will also be presented comprising of residents from three specialist dementia care units in northern Sweden; two in the experimental group and one in the control group. In each setting, sensor data were analysed using state-of-the-art knowledge-driven interpretation techniques based on Semantic Web technologies. Patterns of sleep, physical activity, daily living activities, and stress/anxiety over time were identified. Through specific user interfaces, clinicians and formal caregivers were able to monitor the sensor recordings and the relevant analysis in order to propose new, or to adapt older, supports and interventions. Results indicate that such sensor-based information can have a positive impact on the assessment of BPSD in residential care settings. While at home, the person with dementia and their family caregiver could monitor summaries of their own activities, and read personalized messages, prompts and advice, thus providing timely support and enabling independent living for longer.

PO3.43. Lessons learned from a personalized music program for persons living with dementia at home and in long-term care
McFADDEN Susan, PREMAN Sharayah, HERMUS Nathan

The Wisconsin Music & Memory (WI M & M) program has developed the most comprehensive, wide-spread use of personalized music for persons with dementia in the USA. The WI M & M program employs iPod shuffles loaded with favorite music of individuals with dementia determined through interviews with them and family members. They listen either with headphones or through small speakers. Based on the national MUSIC & MEMORY program, the WI M & M program serves residents in over 250 nursing homes as well as assisted living facilities and other organizations that work with persons with dementia. Regularly scheduled webinars bring together researchers and practitioners to share information about implementation and measured outcomes for diagnosed persons, long-term staff, and care partners. For example, one recent study showed a 4.64% decline in use of psychotropic medications in WI M & M facilities compared to a 3.12% decline in non-M & M facilities (Englebert, 2014). Our M & M research has two components: (1) a pre-post enrollment study of social behaviors of nursing home residents comparing structured, blind observations of persons participating and not participating in M & M and (2) a pre-post enrollment study of persons living at home with care partners examining effects on care partner well-being and the quality of life of the diagnosed individual. This presentation (or poster) will (1) offer preliminary findings from our research, (2) describe interviews conducted to learn about people’s favorite music, (3) report on challenges reported by long-term care staff and in-home care partners regarding their use of the equipment, (4) discuss responses of diagnosed persons to the music, (5) describe reasons why some care partners decide not to enroll in the program,
PO3.44. Short-term psychotherapy for family caregivers – Evaluation of the pilot study

**KILIMANN Ingo, BRAUN CARDOT Tanja, HAUFE Christiane, HAKE Karsten, SCHNEIDER Wolfgang, TEIPEL Stefan J.**

**Introduction:** Family caregivers of persons with dementia (PWD) are the main providers of long-term care for PWD. Caring for a PWD frequently causes burden, stress and depressive symptoms in family caregiver. Psychotherapeutic treatment has shown to be effective, but is rarely used by caregivers. One main reason for not-usage of psychotherapeutic treatment are time constraints on the side of the caregivers. To facilitate for usage of such treatment, we developed a novel short-term family caregiver group intervention.

**Methods:** 10 participants took part in this 12-week program. The major overarching topics were (i) caregiver’s emotional and physical limits, (ii) feelings and emotions towards the PWD and (iii) activation of caregivers’ social resources. Primary outcomes have been feasibility, acceptence and caregiver burden, secondary outcomes self-efficacy (two versions, one for general aspects and one explicitly for caregiving aspects), psychiatric symptoms and social support. Questionnaires have been applied before (T1), directly after (T2) and 3 month after the end of the intervention (T3).

**Results:** The program showed a high acceptance and adherence, all 10 participants stayed into the intervention until the end of the program. The caregiver burden measured with ZBI was stable between timepoints. Two items of the self-efficacy scale showed significant higher values on T3 compared to T1. Significant changes in these items have only been observed in the caregiver aspect version of the questionnaire.

**Conclusion:** Our concept for a short-term family caregiver intervention showed a high level of acceptance and adherence. Subjective burden measured by ZBI was stable without significant changes on T1, T2 or T3. The increase in self-efficacy on T3 compared to T1 needs to be replicated in an independent study. A new study with a randomized control design is currently on the way.

PO3.45. Adaptive implementation of the meeting center support programme in Italy

**CHATTAT Rabih, FARINA Elisabetta, SAIBENE Francesca Lea, RYMASZEWSKA Joanna, SZCZESNIAK Dorota, EVANS Shirley, BROOKER Dawn, MEILAND Franka, HENDRIKS Iris, DROES Rose-Marie**

**Background:** MEETINGDEM, a JPND research study, concerns the adaptive implementation of the Meeting Center Support Programme (MCSP) for people with dementia and their carers, which was developed and positively evaluated in the Netherlands, in 3 European countries (Italy, Poland, UK). Starting with this model a country specific implementation plan for setting up a Meeting Centre (MC) was developed in each country. Results on the implementation of the MCSP in Milan (Italy) will be reported.

**Methods:** Firstly, a meeting was held, to inform care, welfare and volunteer organizations involved in dementia care about the project. Secondly, an Initiative Group was established to identify potential facilitators and barriers to setting up a MC and to suggest solutions for successful implementation. Third a detailed implementation plan was prepared, describing key aspects of MCSP (target group, programme, location, personnel, financing, collaboration between organisations) and country specific adaptations.

**Results:** At a micro level the inclusion of psychosocial interventions within the memory clinic’s treatment plan was seen as a facilitator for the acceptance. At a meso level the MCSP fits well within the local dementia care network in Milan. At a macro level the national dementia plan promoting collaboration between care and welfare organizations appeared to facilitate the cooperation; The main adaptation of the MCSP in Milan are: decrease in the frequency of the programme (three half days a week) due to the MC being integrated in a community centre for older people, aiming to promote social integration; the recruitment of certified personnel. Furthermore the programme will give attention to cognitive stimulation in accordance with the professional orientation and the level of cognitive impairment of the people involved.

**Conclusion:** The successful and effective transfer of care models between European countries should be based on a careful adaptive implementation process, using local facilitators and make the necessary adaptations.

PO3.46. Peer support service for carers of people with dementia

**MARGIOTI Eleni, VLACHOIANNI Angeliki, KALLIGEROU Faidra, SAKKA Paraskevi**

The challenge of being a carer of a person with dementia has been well recognized and assessed. Many programmes are being conducted to support carers and relieve their emotional and practical burden. In 2014, Athens Association of Alzheimer’s Disease and Related Disorders (AAADRD) introduced a volunteer peer support service for family carers for the first time in Greece. Talking to peers may relieve emotional stress, strengthen coping and provide knowledge on caregiving skills.

10 former and current family carers from Athens volunteered to participate in a 2 day training course designed to promote peer support within families of people with dementia. Participants were provided with information on Alzheimer’s disease and other dementias and were taught skills concerning coaching, coping and conversation techniques. Experienced health care professionals (psychologists, social workers, nurses) carried out the training programme. Upon completion trained peer support workers provide peer support through conversations over the telephone or in small groups of carers that place weekly in the 4 Day Care Centers of AAADRD. This service is disseminated through our website and through the local health and social care services.
Participants express satisfaction from sharing experiences and relieving their burden. They also state that they gain a lot of emotional and practical support from peer support workers and from other peers in the group. Eventually, they discover that their role as carers is meaningful and interesting, and they feel motivated to continue. They also feel that the training courses are well planned to prepare them for their tasks.

Peer support can be an important post-diagnostic support service to families living with dementia. It helps carers who face isolation and exclusion and provides suitable volunteers with former caring experiences the tools they need to perform and enjoy peer support work.

**PO3.47. MARIO: People with dementia’s perceptions of robot companions and their potential to reduce loneliness and isolation.**

CASEY Dympna, MURPHY Kathy

**Introduction & background:** Many people with dementia experience social exclusion, loneliness and isolation which contribute to further cognitive decline. The use of ICT solutions to combat isolation and loneliness in people with dementia to act as companions show much promise.

**Aim:** The MARIO Horizon 2020 research project aims to manage active and healthy ageing by developing robot companions based on the needs of people with dementia and their carers to help reduce isolation and loneliness.

**Methods:** A qualitative interpretive descriptive design based on the work of Thorne (2004) was used in the first phase of this study to investigate how robots could be designed that best meets the needs of people with dementia. Three focus group interviews with people with mild/moderate dementia were undertaken. Participants were either living in the community or residing in long term care. Thematic analysis was used to analyse the data and the criteria identified by Lincoln and Guba (1985) was used to ensure and maintain rigor.

Ethical approval was obtained from the University ethics committee.

**Findings:** Findings indicate that people with dementia are receptive to having a companion robot within the home, but less inclined to have the robot accompany them in public. All participants felt that the robot could prompt and remind them with various activities including eating, drinking and when to go shopping. Others functions that MARIO could support included orientating them around the house, cooking and baking and reminding them of social events, family birthdays and anniversaries. The ability to have face recognition was also seen as key as well as engaging in preferred games or hobbies with MARIO. This work reveals that people with dementia are accepting of MARIO and could see its potential in helping retain cognitive abilities and reduce isolation and loneliness.

**PO3.48. Cognitive rehabilitation and cognitive support technology for persons with early stage Alzheimer’s disease**

ØKSNEBJERG Laila, WALDEMAR Gunhild

Cognitive rehabilitation and easy-to-use advanced technology has great potential to address the disabling cognitive symptoms of dementia.

The Danish Dementia Research Centre has created an innovative technology-based cognitive rehabilitation programme. The programme consists of individualised counselling and group intervention offering education on cognitive symptoms in early Alzheimer’s disease (AD), strategies and practical aids and tools to cope and compensate for these symptoms and individualised learning and training of these compensating strategies, aids and tools. Mini iPads with an individualised set up of apps are provided for all participants as a main tool to support and compensate for cognitive dysfunction.

This 14 week intervention programme has been investigated in a pilot study involving 11 persons with early AD and their caregivers. Results of the pilot study showed that the programme is both feasible and applicable. In general, patients with early AD are capable of using tablet based technology, but the results underlined a lack of more readily accessible software/apps that fit the needs of people with declining cognitive functions, and it also pointed to the need of solutions to support hardware and software maintenance.

We are planning a Danish multicentre study to investigate the clinical effect of the intervention programme, including software that will be specifically developed to meet the needs of people with dementia.

**PO3.49. Improving access to psychosocial interventions for caregivers and people with dementia.**

MILDERS Maarten, BELL Stephen, LORIMER Angus, JACKSON Heather

The increasing social and economic costs of dementia have led to calls to develop cost-effective and accessible care for people with dementia and their family caregivers. Multicomponent programs, comprising carer education and psychosocial interventions for the person with dementia, have shown to be particularly effective for maintaining well-being and daily functioning. However, these programs are typically labour-intensive for health care professionals, and therefore expensive, hindering widespread access.

The aim of this project was to improve access to a multicompont program for caregivers and people with dementia. The manual-based program contained caregiver education about dementia, coping with the caring role and engaging the person with dementia in meaningful, stimulating activities. Unlike most previous programs, caregivers were trained to present part of the intervention and most trainers came from local charities and voluntary organisations, rather than health care services.

Trainers from 6 organisations, only one involving health care, were
PO3.50. Involving family caregivers of persons with dementia in the development of an online psycho-education tool

SPRUYTTE Nele, VAN VRACEM Marieke, DECLERCQ Anja, VAN AUDENHOVE Chantal

This study aims to develop and evaluate a web-based psycho-education program for family caregivers of people with dementia on the non-pharmacological management of night-time agitation. Causes of night-time agitation are multifactorial. In order to be effective, the tool needs to respond to the specific needs and questions of family caregivers. This presentation focuses on the participation of family caregivers in the development and refinement of the psycho-education tool.

First, the experiences of both professional and family caregivers in the sensory and spatial management of agitation were investigated in 3 expert panels and confronted with literature on sensory and spatial factors that contribute to agitation. As a result, the focus of the intervention is narrowed to night-time agitation.

The knowledge from literature and practice experience is then integrated into an online psycho-education tool which aims to inform and guide family caregivers through the variety of causes and strategies of coping with night-time agitation.

A second step of participation involves expert panels where family caregivers (n=20), recruited through Alzheimer Association and other organisations, were presented the tool on paper and asked to provide additional input and practice examples, to comment the content and form of the tool and to anticipate on potential barriers and facilitators for the implementation of the online tool. These expert panels permit additional input and practice examples, to comment the content and form of the tool and to anticipate on potential barriers and facilitators for the implementation of the online tool. These expert panels permit additional input and practice examples, to comment the content and form of the tool and to anticipate on potential barriers and facilitators for the implementation of the online tool. These expert panels permit additional input and practice examples, to comment the content and form of the tool and to anticipate on potential barriers and facilitators for the implementation of the online tool.

Psychosocial interventions that support family caregivers can benefit from active involvement of these family caregivers, and this throughout the whole research process (from initial development to evaluation).

PO3.51. Using digital technology creatively to connect health professionals and people affected by dementia in rural areas

GRAY Patrick, MUIR Sarah, PASCOE Ann

To show how a partnership using digital technology connected Allied Health Professionals (AHP) in city mental health services to people affected by dementia in rural Community bases in the Scottish Highlands.

How using digital technology made AHP services more accessible to people in rural settings and increased the time AHPs spent in direct contact with a larger number of people. Previously without technology, time was spent travelling instead of reaching people affected by dementia in more timely and economical ways.

How professionals working with a dementia friendly community invited people affected by dementia in rural areas to tell them what interested them by using pictures and how together they were able to build up a photographic bank of images of specific interest to community groups around the Highlands.

How by using specific themes e.g. feet, colour and/or celebrate they engaged with those community base using digital media to highlight and share interests. How this project flexibly engaged people individually and in groups with face to face meetings, via social media e.g. twitter and Facebook or by using emails, telephone, letters, iPad, dvds and memory sticks. How community hubs developed their potential to work with central AHP services to facilitate therapeutic interventions.

How the bank of images served many purposes: how these programmes offered a basis for interaction between the Health Professionals and people affected by dementia using smart television, video conferencing, skype etc. How this project also developed a range of different resources including health programmes around exercise, nutrition, diet etc.

How more resources were better directed to interactive support via digital technology thereby reducing isolation and loneliness, while ensuring travel and face to face contact became an investment that was planned and more fairly shared across rural communities.

How co-production of this project engaged people affected by dementia and communities at every stage in its development and how this served to improve overall social cohesion.

PO3.52. Dance movement therapy with people with dementia

ŠOŠTARKO Mojca

Dance-movement therapy, based on the principle of unity of body, mind and emotions (Payne 1992) with individual’s movement reflecting patterns of his/her thinking and emotional patterns is a suitable form of therapy for people suffering cognitive decline and having difficulties in expressing their thoughts and emotions (Kowarzig 2006). While the personality is not effected by the cognitive decline, the DMT approach focuses on activation of the preserved abilities and creating a supportive environment where an authentic
PO3.53. Creating a friendly service model in support of persons with mild cognitive impairment in Hong Kong

WONG LAW Gemma Kam Chu

In Hong Kong, there is no direct service provided to young people with Mild Cognitive Impairment (MCI) or Alzheimer’s diseases (AD). However, the number of young people with MCI or AD is noticeable for the past five years. Family caregivers looking for services for their young partners or siblings with MCI or Alzheimer’s Diseases have increased. Dementia care is not yet a subsidized service from Hong Kong Government. The current approach for supporting older adults of different stages of Cognitive Impairment is the provision of in home service and or day care services in community. The lack of support services for young onset would have negative impacts on the young age group with newly diagnosis. For example, one male client who returned to the centre after attending the first consultation at the Memory clinic claimed that he felt “he has been labeled with the diagnosis of Alzheimer’s disease”. His wife sought professional help when her husband withdrew himself from going out for a number of months. The qualitative study aimed to explore the perception and feeling for the first consultation at the Memory clinic. Twelve cases were identified to fit into the criteria for in depth interview. Preliminary results show that the young age group has denied or were reluctant to seek professional help due to a lack of formal and informal supports in community. Their delay seeking help behaviour has caused the concerns amongst the health professionals. Other findings showed that cultural belief and health practice are associated with seeking behavior for professional help at early stage. It is thus important to understand the pathway from onset to finally receive treatment & care so that a unique service model of care for young onset can be developed for Chinese population.

PO3.54. Medico-legal evaluation of dementia: validation of a multidimensional assessment grid

FABBO Andrea, De VREESE Luc Pieter, GIULIANI Giuliana, BRUNO Patrizia, BARTORELLI Luisa

Introduction: The medical-legal assessment of civil invalidity (CI) with voucher (€508.55 monthly), in persons with dementia (PWD) is complicated by uncertainty and fragmentation of laws and regulations and the absence of a standardized (i.e. objective) method of assessment.

Aim and methods: An innovative multidimensional assessment grid, proposed by the Italian Psychogeriatric Association, was applied by an expert psychogeriatrician to 1,273 consecutive person with dementia (PWD) who acted as external consultant of the Medico-Legal Boards for Disabled of the Local Health Authority of Modena.

The grid evaluates functional status (IADL, ADL), locomotion (Timetti), dementia severity (MMSE, CDR) and concomitant organic comorbidity (Comorbidity index at CIRS). The aim of the study is to verify the capacity to predict by means of the grid’s total score subdivided a priori into three levels of severity of clinical impairment (severe: 0-6; moderate: 7-8; mild to absent: 9-12), the three possible decisions made by the Board (civil invalidity (CI) of 100% with voucher CI of 100% without voucher, CI <100%), using the area under the Receiver Operating Characteristic curve.

Results: PWD median age was equal to 84.5 years with a female predominance (66.1%). Probable Vascular dementia was the most prevalent form of dementia (n = 452) in this sample, followed by Probable Alzheimer’s dementia (n = 330). The areas below the ROC curve of these three scores predictive of the Board’s decision, were 0.92; 0.69 and 0.92 for CI of 100% with voucher, CI of 100% without voucher, CI <100%, respectively. A logistic regression analysis showed that CDR, Timetti and MMSE scores in order of importance predict significantly the recognition of an economic support to PWD and their families, explaining almost 62% of the variance and classifying the PWD with an overall accuracy equal to 94.8%.

Conclusion: These results confirm the validity of this multidimensional evaluation grid in the medical-legal field and should act as a stimulus to both the Forensic Medicine and Geriatrics to elaborate together with the National Institute of Social Security a shared standardised protocol for the assessment of the variegated conditions of disability in PWD in relation to their “multidimensional context” of life and care.

PO3.55. eHealthMonitor: Informal caregivers’ perspectives on a tailored eHealth support service within the community

SCHALLER Sandra, MARINOVA-SCHMIDT Velislava, SETZER Manuela, SCHMIDHUBER Martina, FREWER Andreas, KOLOMINSKY-RABAS Peter

Background: The European eHealthMonitor project (eHM) developed an individual and interactive web portal for the Dementia care setting: The eHM Dementia Portal. It aims to provide targeted...
PO3.56. Cross-national differences in the psychological profile of caregivers of people with dementia in Europe

Introduction: People with dementia generally require a high level of care, and informal caregivers such as spouses and daughters are the ones that provided it. Dementia has an important impact on these informal caregivers, who manifest a high prevalence of health and psychological problems. Although numerous studies have revealed a psychological profile of these caregivers, there is a lack of studies that compare this profile among European countries.

Objective: The main aim of this study is to analyze caregivers’ socio-demographics and psychological aspects to explore possible differences in the caregiving of three European countries (Spain, Denmark, and Poland).

Method: One hundred and one primary informal caregivers (Spain n=39, Denmark n=31, Poland n=31) of people with dementia were recruited. Socio-demographic information, aspects related to work situation, context of caregiving, types of support that caregivers used, care-recipient characteristics, social support, self-rated health, depressive symptomatology, sense of competence and perceived satisfaction with caring were recollected.

Results: Significant differences were observed among countries in caregiver age (F(2,96) = 8.6), type of family relationship (Chi-square = 30.5), leave the work to take care of the relative (Chi-square = 9.3), caregiving weekly hours (Chi-square = 8.8), psychoactive drug intake (Chi-square = 8.2), caregiver level of cognitive impairment (Chi-square = 22.8), caregiving satisfaction (F(2,98) = 16.9), and in several types of support.

Conclusions: These results address important differences among European caregivers and therefore, they map which characteristics should be taken into account when studying the caregiving process in these countries. These findings appear useful for developing a better caregiver health care compromise in Europe.

PO3.57. Integrative Validation Therapy (IVA) in a long-term care facility for people with dementia.

ERDMANN Anke, SCHNEPP Wilfried

In order to accord people with dementia more respect and appreciation, Naomi Feil developed validation therapy which has been modified by Nicole Richard since 1993 and which has resulted in Integrative Validation Therapy (IVA). Since then, IVA has been implemented in many care facilities in Germany and some other European countries.

Research questions: Two research questions were examined: 1. With which categories can we describe the praxis of Integrative Validation? 2. How is Integrative Validation evaluated by nurses and relatives?

Methods: A Fourth Generation Evaluation Study was conducted with IVA practitioners, IVA trainers, a neurologist/psychiatrist and relatives of people with dementia living in a care facility in Germany. The participants were questioned on their experience with Integrative Validation Therapy in 18 individual problem-centered, guideline-based interviews. These interviews were supplemented by four unstructured participating observations of interactions between IVA practitioners and residents in the care facility. The results of the individual interviews and the observations were validated in a group discussion, inconsistencies were resolved and unresolved questions were answered to the best possible extent. The questions remaining unresolved were discussed in a further group with the originator Nicole Richard and 14 IVA trainers. The result of this Evaluation is a case study on the implementation of Integrative Validation in a care facility.

Results: The empirical study led to the development of a model of Integrative Validation Therapy describing conditions, components and outcomes of Integrative Validation in the case investigated. In
PO3.58. A self-management tool for people with dementia and their carers

MCLEISH Kate, JARVIS Rebecca, HILL Derek, DE WAAL Hugo

One in five of us will get dementia if we live long enough. There is a growing need to provide post-diagnostic support to more people. With little advance in pharmacological approaches, we need interventions that make a difference. Internet usage by over 65s rose 27% in 2012/13 so web-based tools are an attractive option for people with dementia and their carers.

We have developed a tool which:

- puts the person with dementia at the centre of their care
- reassures family members
- helps professional health and social care workers provide support
- alleviates the isolation that people with dementia experience.

The tool is a web-based platform which enables people to record important information, such as their interests, likes and dislikes, daily routines, concerns. This allows them to 'build' their own personalized action plan. People with dementia and their carers have informed the features and design.

Populating the tool is a joint exploration of someone’s individuality. Even close family members report being surprised how it has unearthed previously unknown issues and events in someone's life. An action plan is distilled directly out of this material which is unique and relevant to the individual, in contrast to traditional care planning, which often is experienced as not taking someone's personhood into account or neglecting important issues. Being online, it is always available, can be updated and shared according to the person’s preferences including with service providers and family and friends who may live a long way away providing valuable reassurance to them.

A prototype has been evaluated with 20 people with dementia and 18 carers to inform design modifications and new features. Responses were extremely positive with 37 out of 38 participants saying they would like to use it again. We continue to develop and evaluate the tool including availability in multiple languages.

PO3.59. Caring for people with dementia in the dementia-friendly pharmacy? – presentation of community projects in pharmacies and findings from evaluation

PLUNGER Petra, TATZER Verena C., REITINGER Elisabeth, HEIMERL Katharina

Background: People with dementia and their caregivers face many challenges in the complexity of health care systems. Issues such as lack of integration of services (Höfler, Bengough, Winkler, & Griebler, 2015) and stigma are challenging for people with dementia and their informal caregivers in Austria. Moreover, people with dementia may have other health issues that lead to complex medication management.

Methods: The project “Dementia-friendly Pharmacy” uses a participatory research approach to promote the health and quality of life of people with dementia and their caregivers. In this approach, knowledge is produced in collaboration with the pharmacies, the local self-help group “Alzheimer Austria” and caregivers of people with dementia.

Results and Discussion: In the middle phases of the participatory research project, workshops for community pharmacists were created covering the topics of “pharmaceutical care”; “networking in the community” and “communication”. In the current phase of the project, the pharmacies conducted pilot-projects in their individual pharmacies based on a needs-assessment with caregivers of people with dementia.

These projects range from issues related to the core-business of pharmacies - to improve the pharmaceutical care for people with dementia and networking with local medical doctors - to community-projects. The richness and creative approaches of the individual pharmacies in their local context is inspiring and shows the usefulness of a systemic approach in the local community.

A conceptual analysis of the projects and what “care” means in the context of dementia and pharmacies, three basic processes were identified: pharmaceutical care; informal consultation on care issues and community based activities. Raising awareness and networking with partners in the community are other vital elements of the “dementia-friendly pharmacy”. Examples of individual projects, issues of sustainability and the role of “dementia friendly pharmacies” in the public health context will be presented together with results of the projects evaluation.

PO3.61. Professional evaluation with persons with dementia and family carers: case managers’ dilemmas

KETELAAR Nicole, JUKEMA Jan, VAN BEMMEL Marlies, ADRIAANSEN Marian, SMITS Carolien

Introduction: Case manager’s offer prolonged support to their clients: people with dementia and their family carers. They coordinate various care and well-being services. Evaluating their professional work may improve its quality and indirectly the quality of their clients’ lives. This study aims to provide insight in the way case managers evaluate their work.
PO3.62. Interaction between case managers and persons with dementia or their family care givers: theory and tools, based on international practice.

SMITS Carolien, AAN DE STEGGE Cecile, JUKEMA Jan, SPRUYTTE Nele, PIANOSI Birgit

Introduction: People with dementia and their family care givers interact frequently with their case manager. This interaction is meaningful to both people with dementia, their carers and the case manager. Case managers aim to offer person centered care, but need support to achieve optimal interaction. This study supported case managers and their clients, by constructing and evaluating interaction tools in case management practice.

Method: We used Practice Development in an action research approach. Four communities of practice (COP) in The Netherlands, Belgium and Canada were established. During twelve months these COP’s constructed and implemented improvement plans focussing on the quality of the interactions. Teams could choose their own goals. Researcher-coaches and higher education students supported the COP’s.

Results: The efforts of the COP’s, the students and the researchers resulted in new insights and tools. The case managers piloted these tools in practice and reflected on their meaning. The tools concern three interaction domains: (I) Context of interaction: (a) health literacy observation list, (b) Sociogram (c) Energy diary for family care givers (d) Communicative style detection list (II) Interaction: (a) Telephone Interaction Facilitator (b) Interactive scenario choices regarding education (c) Self evaluation in Motivational Interviewing (III) Tools for reflection on interaction: (a) Self reflection on interaction; (b) Reflection on Motivational Interviewing (c) Communication Cues (d) a translated DEMTEC. Furthermore, the validity of a communication model (De Haes & Bensing) was explored for case management. This presupposed a shift from ‘client’ to ‘personal network’.

Conclusion and Practice implications: Developing tools for case managers in an international context is complex. Nevertheless, the resulting model and tools, based on careful piloting and critical reflection, are promising. Their practice based development trajectory may facilitate actual use by case managers in the immediate future. However, they need further testing before implementation in international practices.

PO3.63. Experiences in dementia care networks in using an interactive web tool for making shared decisions

SPAN Marijke, SMITS Carolien, JUKEMA Jan, GROEN-VAN DE VEN Leontine, JANSEN Ruud, VERNOOIJ-DASSEN Myr, EEFSTING Jan, HETTINGA Marike

Background: In an earlier study we developed the DecideGuide, an interactive web tool for facilitating shared decision-making in dementia-care networks. The DecideGuide provides a chat function for easier communication between network members, a deciding together function for step-by-step decision-making, and an individual opinion function for eight dementia-related life domains. The aim of this study was to gain insight in the user friendliness of the DecideGuide, user acceptance and satisfaction, and participants’ opinion of the DecideGuide for making decisions.

Materials and methods: A 5-month field study included four dementia-care networks (19 participants in total). The data derived from structured interviews, observations, and information that participants logged in the DecideGuide. Structured interviews took place at the start, middle, and end of the field study with people with dementia, informal caregivers, and case managers. Four observations of case managers’ home visits focused on members’ responses and use of the tool.

Results:
- The user friendliness of the chat and individual opinion functions was adequate for case managers and most informal caregivers. Older participants, with or without dementia, had some difficulties using a tablet and the DecideGuide. The deciding together function does not yet provide adequate instructions for all users. The user interface needs simplification.
- User acceptance and satisfaction: everybody liked the chat’s easy communication, handling difficult issues for discussion, and the option of individual opinions.
- The DecideGuide helped participants structure their thoughts. They felt more involved and shared more information about daily issues than they had done previously.

Conclusion: Participants found the DecideGuide valuable in decision-making. The chat function seems powerful in helping members...
PO3.64. Focus on dementia in acute care – changing minds, improving lives in Scotland

JOHNSON Amanda, MANTLE Ruth

Improving acute care was one of two key change areas in Scotland’s first (2010) and second (2013-16) National Dementia Strategy, to ensure that, when admission to hospital is unavoidable for people with dementia, the care experience is safe, coordinated, dignified and person-centred. In support of Commitment 10 of the second National Dementia Strategy, ten care actions have been identified to support the implementation of the Standards of Care for Dementia in acute hospitals. This project forms part of the ‘Focus on Dementia’ programme, a partnership between the Scottish Government, Joint Improvement Team and Alzheimer Scotland. The programme focuses on four of the ten care actions: identifying leadership structure to monitor and drive improvements; developing the workforce against the Promoting Excellence framework; working as equal partners with families & carers; minimising & responding appropriately to stress and distress.

An improvement collaborative approach with Alzheimer Scotland Dementia Nurse and Allied Health Professional (AHP) Consultants and multidisciplinary teams within each NHS Board in Scotland is being taken to support this work. This approach supports NHS Boards to build capacity and capability for improvement, to share data, progress, challenges and opportunities. A measurement framework and data reporting tool were developed in collaboration with the NHS Boards. Quantitative data for improvement is being gathered on an ongoing basis. Qualitative data is being gathered through a variety of approaches to understand staff, carer and patient experience of dementia in relation to co-ordination of care and safety and how the care actions in acute care are impacting on these elements. The results of this work will inform the National Dementia Strategy for Scotland in 2016 and will make recommendations about the adoption, spread and sustainability of this model across Scotland.

PO3.65. Innovative approaches to care - care focused on the individual

CJURA LUCI Rosana, NOVLJAN Medeja, VILFAN Blanka

Until 2020, the Resolution of the National Social Protection Programme provides for increase the ratio between the users of community forms of social protection and the users of institutional forms of social protection.

Currently, this ratio amounts to approximately one to two, which means that for one user of community forms of social protection there are two users of institutional forms of social protection.

Until 2020 the aim is to significantly strengthen community forms of social protection, increase the number of their users and not to further spread the institutional care more than it is necessary (ReNPSV 13-20, OG of the RS, No. 39/2013).

In the Institute for care at home (ZOD), we have many years of experience and a high standard of services. In the framework of an individual approach and comprehensive treatment of individuals we want to complement existing services in the context of other health care services at users’ home, namely physiotherapy, occupational therapy, speech and language therapy, psychotherapy and nursing, which is a novelty in the Slovenian area and represents an important step forward towards a modern approach of working with elderly at home.

Based on the search of various and additional options for a new approach to work with the users, the demographic situation of the population in the Municipality of Ljubljana (MOL), and thereby an increase need for specialized approach to work with elderly, and based on many years of experience in direct work with users, acute needs of the assistance for people with dementia and their families, and based on the initiative of the founder, we believe that dementia needs a special attention in the Municipality of Ljubljana.

An organized home care would offer professional and comprehensive approach to the persons with dementia and facilitate the home care to their families.

PO3.67. Small scale living for people with dementia “Cornelia Hoeve”

KEUNING-PLANTINGA Annette, FINNEMA Evelyn

Background: The “Cornelia Hoeve” is a small-scale home where twelve people with dementia live. Care is based on the belief of the importance of the surrounding on the mood and behaviour of persons with dementia. The care is person centered; residents can follow their rhythm of life as they were used to.

Research goal: Describing and evaluating the aspects from the care concept that influence the quality of life of the residents of the “Cornelia Hoeve” from the perspective of the person with dementia, the family caretakers and the nursing staff.

Method: The research consists of desk research and a mixed method design. The Mini Mental State Examination (MMSE) (Folstein, Folstein, McHugh,1975) is used for determining the cognitive impairment. The Qualidem (Ettema et.al, 2005) is used for the measurement of the residents’ quality of life. Interviews have been done with the residents, their family caretakers and nursing staff in combination with participative observation.

Results: The residents of the “Cornelia Hoeve” are satisfied with their apartments, the food, the atmosphere and some of the activities, although this varies per person. Most residents don’t initiate activities without help.

Overall family members are positive about the personal approach of care being provided, the physical space of the residents and the communication with the nursing staff. However, communication with the staff at the same time is also mentioned as a point for improvement. Family members indicated that the activities done at
the care farm are not appropriate for and meaningful to all residents. The nursing staff experiences the work environment as pleasant due to the positive contacts with residents, family, and colleagues. The nursing staff wishes improvement of daily activities. Based on the results further research is recommended focusing on which activities are appropriate and meaningful for residents in different stages of dementia.

PO3.68. Education within dementia care
DØBLE Betty Theodora Sandvik, REGGESTAD Marta Sofie

As part of the Norwegian Dementia plan 2015, an in-house educational program is implemented in the primary care systems. The ABC-program consists of theoretical material in three booklets, study groups for multidisciplinary reflection and semi-annual seminars, aiming at developing expert knowledge in primary health care for persons with dementia. Each booklet is expected to be completed within one year. One includes theories around person-centered care, and environmental treatment.

Methods: Ageing and Health has been assigned responsibility for implementation of the education and coordinates the teaching conducted by our collaborators in primary and specialist care. Successful completion requires that all booklets are read, and that participants attend at least 80% of group meetings and seminars. All participants receive a certificate of competence.

Professional caregivers and unskilled employees are equally eligible to enroll in the course. This model has been approved by diverse professional trade unions as part of a specialized clinical training. The program cooperates with a model for skills upgrading too, which lead to formal qualification as health-care worker.

Results: More than 94% of the Norwegian municipalities take part in the education, 20,000 caregivers from a variety of disciplinary backgrounds have participated. Of these 22% where nurses (RN), 57% were enrolled nurses or skilled workers, 2% assistant occupational therapists and 12% were unskilled careers. Recruitment to the skills upgrading program increases. Over 400 employees participate and 71 have passed the exam in Health Work. In the primary care systems leaders aligns, and gives attention for the educational programs.

PO3.69. Innovative care - Person centered care
PRAPER Maja, ZAGORC Simona

Homes for elderly in Slovenia have been changed dramatically in last 10 years - transformation started with person centered care and reflects smaller size of buildings, colorful painted in nice warm shades, equipped with comfortable furniture and personal belongings of tenants which contribute towards homeliness and through nice atmosphere create wellbeing.

New psychosocial paradigm has changed the content of services and enhanced their quality - the influence of consideration and respect of individual’s dignity and needs powerfully influenced also on approach of employees, regardless to their education or field of work. Individual centered care was automatically continuing of the transformation change, started through new psychosocial concept and is built on principles of active participation of each tenant and his/her family or caregiver, complementary integrated multidiscipline approach, based on individual plan and appropriate chosen services.

We are going to present few examples of good institutional practices in Slovenia, which is oriented into creating of family like environment, considered the principles of deinstitutionalization and normalization.

PO3.71. Supporting carers of people with dementia in the UK with peripatetic specialist admiral nurse clinics
WEATHERHEAD Ian

Admiral Nurses are dementia specialist nurses working in various health and care settings in the UK. In 2013 and 2014, Admiral Nurses provided 1:2:1 drop-in clinic sessions for families at two national Alzheimer’s Shows in the UK. The clinics proved extremely popular and accommodated a high volume of visitors from all parts of the UK seeking information on many aspects of dementia, key subjects and percentages of each as follows:

- Physical health and wellbeing of the person with dementia 82%
- Mental health and wellbeing of the person with dementia 72%
- Skills in coping with behaviour / symptoms 72%
- Knowledge and understanding of dementia 58%
- Mental health and wellbeing of the carer 58%
- Practical support 44%
- Physical health and wellbeing of the carer 34%
- Understanding treatments and managing medication 24%
- Allowing time for self (carer) 24%
- Looking to the future (carer) 17%

To help address the needs identified, Dementia UK will develop Peripatetic clinics both in the community and in the workplace as follows:

1. In partnership with the Charity for Civil Servants, Admiral Nurses will provide 1:2:1 clinics in two workplace sites in the UK monthly for a year. The clinics will offer appointments to employees who may not have access to specialist dementia services or support, and who may also find it difficult to take time off work to attend appointments. Admiral Nurses will also provide educational sessions to managers on site to help understand the needs of carers, and promote greater flexibility for staff who are carers. Admiral Nurses are dementia specialist nurses working in various health and care settings in the UK.

2. Dementia UK will develop roadshow clinics around the UK. Working with local stakeholders and commissioners, Admiral Nurses will provide 1:2:1 clinics across the country increasing access for carers to specialist nurses. This pilot will be unique in delivering Peripatetic Dementia Care Admiral Nurse clinics across the UK.
PO3.72. Using the Logic Framework to model complex nursing interventions with families living with dementia: Admiral Nursing in the Community

MAIO Laura, BOTS福德 Julia

Evidencing the impact of work carried out with clients is increasingly becoming a requirement in the healthcare sector. The Francis Report in the UK highlighted how meeting targets isn’t sufficient to ensure quality of care. A more rounded approach, looking at actual outcomes for clients, offers a better way to explore service’s effectiveness. However, unpicking complex interventions can be challenging. Admiral Nurses, specialist dementia nurses, aim to provide holistic and person-centred support to families living with dementia, working in the community and other settings; interventions can be very complex and multidimensional.

To support teams working in the community to evaluate their work, we adopted a project approach developing a Logic Framework by conceptualizing the caring continuum as an ongoing but more discrete project, multi-layered dynamics can be more easily articulated, facilitating and focusing the evaluation process.

As a tool, the Logic Framework is widely used in the International Development field and has been developed from the late 60s onwards. It facilitates the process by breaking project cycles down into constituting elements (Situation, Inputs, Outputs and Outcomes in the Short, Medium, and Long term) and by visualizing causal connections. This promotes informed reflection on impact dynamics, enhanced understanding and more informed choice of indicators, whilst supporting ongoing collaborative work and open negotiations between stakeholders.

The model that will be presented in this poster is based on data derived by questionnaire responses of family carers in receipt of Admiral Nursing support and observations on clinical work from Admiral Nurses. It was subsequently reviewed by Admiral Nurses and Business Development Officers and will find application in informing local evaluations of Admiral Nursing Teams, as well as support negotiations with commissioners.

This approach can find vast applications across the board, for both clinical and non-clinical work, promoting accountability and reflective practice.

PO3.74. Norfolk admiral nurse pilot: an evaluation report

ALDRIDGE Zena, FINDLAY Nicola

The Admiral Nurse Service was launched in Norfolk in 2013 for two main reasons: firstly as a direct response to the narratives of the carers of dementia patients and secondly from an examination of Norfolk’s demographics that highlighted a significant need for the service. 20.8 percent of the county’s population is aged over sixty five and 10.1 percent is aged over seventy five. The significance of these statistics is emphasised by the 2011 census, showing that 16 percent of the UK was aged over sixty five.

During the two year pilot of the Admiral Nurse Service, a detailed and independent evaluation was carried out, utilising a mixed methods design and considered the views of carers and professionals with equal weighting. The results demonstrated that the service is “invaluable” and the full report is available from Dementia UK. In addition to the clinical outcomes, a cost benefit analysis demonstrated considerable savings, specifically, the Admiral Nurse Service saved health and social care in excess of £443,593 over the period of 10 months.

Furthermore, a new service pathway is proposed taking its evidence base directly from the qualitative findings of the evaluation and this is the focus of this poster. The Admiral Nurse Service in Norfolk now offers tiered support, and its grading is a joint decision between carer and Admiral Nurse. It is based on the carer’s perception of their situation, how able they feel to adopt the role of carer and the impact these will have on their ability to function. The new service pathway proposes that there will be a significant increase in the number of carers that are supported, with a level of support tailored to meet individual needs, whilst further improving on savings to health and social care.

PO3.75. New model of dementia end of life practice - how partnership working can empower people to live well and die well with advanced dementia

HUTCHINSON Deborah, HARRISON Sian, REEVES Caroline

Access to End of Life support for people living with dementia is often very limited, impacting significantly on their experience at the end of their journey. The new Dementia End Of Life Practice Development team in Cheshire, England, is a new collaboration between the End of Life Partnership Group, three Clinical Commissioning Group, and Mental Health set up to improve the experience of, and attempt to address the inequalities for, people living with advanced dementia.

The multi-disciplinary, cross-professional team includes a social worker (team leader), a district nurse (educator/facilitator), a mental health nurse (Admiral Nurse) and an allied therapist. The poster will encapsulate the aims and planned outcomes of the project, illustrating a model of close partnership, working in a structured and reactive way.

The team will look at supporting the wider social and healthcare workforce, as well as the population living with advanced dementia, to plan for future care and recognize the dying phase of the disease. The aim will be to facilitate complete advanced care planning for people with dementia, unlocking and enabling access to holistic, compassionate, palliative and person centered care that results in a peaceful, painless death in a preferred place of care (PPC).

In particular, the project is aiming at achieving the following: people with dementia remaining in their preferred place of care, increase in patient and informal carer satisfaction and experience, reduction in unnecessary hospital admissions at end of life, reduction in length of stay in hospital; reduction in accident and emergency admissions in last year of life; increase in knowledge and confidence of those caring for people with advanced dementia; end of life care as a core
PO3.76. Culinotherapy in Alzheimer’s disease: new strategies and insights for associate non-pharmacological therapies

Rodríguez Arellano José Julio, De la Pisa Niño Lucía, Marcos Muñoz Nieves, Villaverde Noelia González, De Juan Díez-Guerr Flor, Alvarez Roza Amor

In recent years there is an increase interest in developing new approaches for the treatment of dementia and among them Alzheimer’s disease (AD) by using alternative strategies which can be developed in parallel to pharmacological therapies. Culinotherapy (considering both diet habits in a preventive manner and more actively cooking participation and skills) is gaining more and more acceptance and recognition. In this sense, within Alzheimer León we have recently developed a program (“Activate Cocinando”: “Get active cooking”, now in its third year) in which 18 patients in early AD phases are confronted to multiple tasks ranging from managing aliment shopping including simple budget management, to food processing and preparation, culminating in a final prepared dish and degustation done in a voluntary manner considering the patient and family wishes. In this innovative programme we also count with the fundamental help of 18 independent gastronomic professionals and social workers. Our program focus is based in developing a multisensory stimulation approach providing a partial autonomy behaviour by keeping: i) social skills and ii) sensory processing and integration, which know that potentiates cognitive and mnesic functions. So far, we have demonstrated that, first patients are more integrated with their fellows and family reacting in a very active manner and socializing more getting away from isolation behaviour (up to 62 %) with their fellows and family reacting in a very active manner and socializing more getting away from isolation behaviour (up to 62 %) facilitating their interaction and day-to-day activities. In addition, 41, 70 % of the patients increase their attention and concentration levels, which are directly related, with a 31% in both activity levels and long-term memory recovery based on sensory reminiscence. Furthermore, all patients ameliorate their mood and esteem in 57, 40%. Finally, patients seem not only to be more integrated within the day care center but also to show a slower development of the associated cognitive and mnesic alterations associated with AD.

PO3.78. BRAIN FITNES – vaje “ena na ena” po meri posameznika

Lambercar Jasmina

Urjenje spomina in pozornosti, sproščanje in tehnični pomnjenja so dejavnosti, zaobljitev v Možganskem fitnesu, ki pozitivno vplivajo na proces pomnjenja, ustvarjalnost, komuniciranje, počutje, na vsakodnevno življenje osebe z demenco, in hkrati kot preventiva proti bolezni izgubi spomina tudi na zdravje vseh najbližjih, skrbnikov oz. institucionalnega osebja.

Prvi pogoj za uspešno delo trenerja spomina predvsem v začetni stopnji bolezni je, da skrbno vzpostavi odnose z osebo z demenco, da podrobno seznan zm, kulturnim okoljem, ustvarjalnimi obdobji, dejanskih, dogodkov in ljudi, ki so bogatili osebne poti, ter da z vajami, ki spodbujajo umске aktivnosti, seznani tudi svoje. Zaradi upada kognitivnih sposobnosti, slabših sposobnosti komuniciranja, prepoznavanja in povezovanja, je napomembnejša prva informacija s strani svojca, ki tudi v izvedbi dnevnih vaj odигра ključno vlogo. Le z doslednim upoštevanjem življenjske zgodbe osebe z demenco in s prepoznavanjem čustvenih reakcij je Možganski fitnes učinkovit, prijetna dejavnost, smiselna, tudi v razvrednito, opogumljanju, spodbujanju in nagrajevanju. Poudarek je na vajah, ki so sestavljene na osnovi življenjske zgodbe in psihofizičnih lastnosti, prepletene v pet sklopov aktivnosti:
- vaje za izboljšanje pozornosti:
  - delo s čutili (sluh, vonj, otip, vid, okus) in čustvi (jeza, strah, veselje).
- Vaje za kratkoročni spomin:
  - pomnjenje besed, črtek, seznamov, obrazov in imen.
- Z vajami izboljšujemo sposobnost shranjevanja v prički.
- Vaje za dolgoročni spomin:
  - s pomočjo delovnega zvezka in v obliki vodenega pogovora udeleženci organizirajo gradivo, strukturirajo in povezujejo informacije.
- Tehniki pomnjenja:
  - mnemotehnike kot pomoč za enostavno shranjevanje, povezovanje in pričkino informacijo.
- Tehnike sproščanja in vaje za ravnotežje:
  - med hojo, stoge na mestu, med sedenjem.
- Če živimo zgolj za trenutek – tudi minemo z njim. Če trenutek povežemo s spominom, vnesemo trajanje.

PO3.81. Living with dementia – every day

Cvetko Tatjana, Hojjan Vesna, Bizjak Vesna

Background: Recognition of early dementia in family medicine still takes careful steps in management of chronic diseases. Facing the dementia at home is always a challenge for family members. In every case of patient, reorganization of family life is as important as seeking for help and assistance of external social services. In long-term care of patients with dementia, caregivers need a lot of support and practical suggestions how to organize their dailylife and avoid burnout.

Aim: to discuss the recognition of dementia in family medicine and show specific approaches to promote different daily activities in organization of day life of persons with dementia.

Methods: brainstorming session and lectures with practical demonstration and video presentation

Results: Presentation of the programs of social interventions and learning projects about dementia homecare.

Three different projects will be presented:
One day school - Living with dementia every day– parallel program for caregivers and patients with dementia. Caregivers learn about dementia and get some practical skills and information, patients with dementia attend the program of occupational therapy and different activities in daily care
Dementia care at home – program of lectures about personal care and assistance in rural area for lay public with demonstration of handling the immobile patients
Promotion of physical, mental and social activities as a way of preventing burnout of caregivers:
Conclusions: Practical approaches of learning about dementia-care empower family members and provides them the opportunity to learn about dementia and cope with problems that dementia brings to everyday life.

P04.1. Treating Alzheimer’s disease with Neprilysin secreted by adipose derived mesenchymal stem cells?

KELLNER Steven James, REIF Miriam

Alzheimer’s Disease pathology shows accumulations of extracellular amyloid-beta (Ab) containing plaques and intracellular neurofibrillary tau tangles in the brain. It should be noted that Ab is a naturally occurring endogenous peptide that may have normal physiological functions. Pathology associated with Ab is related to its aberrant accumulation/aggregation. The proteolytic degradation of Ab is a major route of clearance. Of these enzymes, neprilysin (NEP) is considered one of the most important for the control of cerebral Ab levels. NEP is primarily expressed in the kidney, however, it occurs at much lower levels in many other tissues, including brain, where it is located on neuronal membranes, both pre- and postsynaptically. Neprilysin occurs naturally in the secretome of the ad-MSC, which is produced in vitro and in vivo as a means of communication from cell to cells and as a reaction to external influences. The secretome of ad-MSC can be harvested as a clinical grade treatment for various illnesses.

Two of the major neuropathological hallmarks of AD, senile plaques and neurofibrillary tangles, take place with the aging of the human brain many years prior to the disease onset. This suggests that aging is the predominant risk factor for AD. In this respect, it is most important that a preventive medicine combined with presymptomatic diagnosis allows a substantial portion of aged people to escape from the scourge of dementing syndromes. There have been many reports indicating that neprilysin expression/activity declines with aging and in AD. Substitution with the secretome from adipose derived mesenchymal stem cells containing neprilysin should be able to prevent AD and maybe even reverse existing amyloid accumulation.

P04.2. Assessing independence of residents suffering from dementia in meeting basic living needs in Ljubljana nursing homes

KOBENTAR Radojka, ZORC MAVER Darja

Background: It is clear that a very high percentage of nursing home residents exhibit clinical signs of dementia, which affect the independence of the impaired individuals. The purpose of the study is to determine the residents’ independence level in performing basic life activities.

Methods: The research examines 233 residents of both sexes, with a clinical diagnosis of dementia that are aged 65 years and over that have resided in one of the four Ljubljana municipality nursing homes for at least one year prior to the beginning of the study. The autonomy in carrying out 11 basic live activities was measured on a three-level scale and their cognitive skills with a quick-test of cognitive
PO4.5. Some differences in areas of cognitive function in Mini mental state examination in the Alzheimer’s and vascular dementia

KRSTESKA Roza, ICEVSKA Liljana

The cognitive assessment have important role in the diagnosis of people with dementia. The most widely used questionnaire in obtaining information on patient cognitive function is the Mini Mental State Examination (MMSE). It's administered by physicians is useful in distinguishing patients with normal cognitive function from ones with cognitive impairment and future appropriate diagnostic and pharmacological access.

The object of the study was to analyze the Mini Mental State Examination in 30 patients with Alzheimer’s and 30 patients with vascular dementia. The study included 60 people with dementia diagnosed with Alzheimer’s or vascular dementia (by ICD 10; MMSE; HIS; CT or NMR). The condition for the patients to enter this study was the age above 60 years. Average age of the patients in the group with vascular dementia is 72.6 years, and in the group with Alzheimer’s dementia is 77 years (p < 0.0043).

The average time from the beginning of the vascular and Alzheimer’s dementia was no statistically significant difference (3, 35±1,876 y. v.s. 3, 9±1,984 y) p = 0.4334.

A significant correlation was found between the average MMSE scores in the group with vascular and Alzheimer’s dementia (16, 8±5.27 vs. 10, 9±5.46) p= 0.0001. According to our results there are more rapid cognitive decline and more severe cognitive impairment in patients with Alzheimer’s than in vascular dementia.

In our study tere were some statistical differences in the question measure that tests the areas of cognitive function: orientation, recall, and language in repetition and three-stages command.

PO4.6. Cognitive training with games: the “giovanni nel tempo” project

BEVILACQUA Petra, De VREESE Luc Pieter, GUIDI Laura, FABBO Andrea, CHATTAT Rabih

Cognitive training interventions are possible and effective in healthy elderly, ameliorating or delaying the rates of age-related decline. Cognitive training in small group settings offer to the participants an enjoyable experience and the benefit of social interaction promoting emotional well-being and combatting loneliness, in addition to cognitive improvements. “Giovani nel Tempo” consists of three board games stimulating working, semantic and episodic memories (Francia R., Guidi L., Bartorelli L. 24th Alzheimer Europe Conference, PO58, 2014). The aim of this semi-experimental study is to verify objectively the preliminary positive impressions collected from seniors who participated into the “Giovani nel Tempo” project, on cognition, emotion and wellbeing in a sample of seniors who regularly attend the Parish of the San Faustino neighborhood of the Municipalty of Modena. The board games sessions, each lasting 90 minutes, will be done twice weekly for two months with the supervision of a Psychologist, expert in memory games and cognitive ageing. Assessments will be done by two expert psychogeriatricians not directly involved in the game sessions at baseline, immediately after and two months later in follow up. The following domains will be explored: cognition (Addenbrooke’s Cognitive Examination Revised); mood (Geriatric Depression Scale-15); physical and mental wellbeing (General Health Questionnaire-12, SF-12 Health Survey) and metamemory (Memory Assessment Clinic Questionaire).

PO4.7. Neuropsychological assessment and trace metal content in urine, hair and fingernails samples from inhabitants of a chemical industrial region (NW Portugal)

CABRAL PINTO Marina, ALMEIDA Agostinho, PINOTO Edgar, ORDENS Carlos, CONDESSO de MELO M. Teresa, FREITAS Sandra, SIMÕES Mário, DINIZ Luísa, MOREIRA Paula, SILVA Maria, FERREIRA DA SILVA Eduard, SILVA LOUREIRO Maria

The surroundings of the Estarreja Chemical Complex (NW Portugal) have an intense industrial activity with negative impact on soil, surface water and groundwater since the early 1950’s, and its population historically relies on groundwater as a source of water supply for human and agricultural uses. This industrial activity produced a large volume of toxic waste solids and liquid effluents, which were disposed in areas that were not prepared for such purpose. During the 1990’s, several rehabilitation actions resulted in an important reduction of the negative environmental legacy. However, we found concentrations (µg/l) of Al, Cu, Fe, Hg, Mn, Pb and Zn in groundwater well above the international and Portuguese recommended values. Less than ~10% of neurologic diseases have a strict genetic aetiology, while the majority have an unknown origin. Occupational and environmental exposures to several metals (e.g., Hg, Al, Mn, Cu, Pb, Fe and Zn)
appear to be a risk factor for neurodegenerative pathologies, such as Alzheimer’s disease, Parkinson dementia, etc. Therefore, the study of the impact of these environmentally-present metals on human health requires further attention and a multi-disciplinary approach, merging neurosciences and psychology with environmental geochemistry. The neuropsychological assessment of a pre-selected population in the studied area is being performed and correlated with the content of selected metals on human biological samples. The experimental sample of this study to date has proved to consist mainly of normal subjects (40.2%), followed by the condition of dementia (36.6%) and the condition Mild Cognitive Impairment (18.3%). This study combined trace element profile in urine, hair and nails with survey information from 100 Estarreja inhabitants to assess the extent to which the biomarkers provide exposure to metals information. Urinary metal levels were elevated, above commonly accepted reference values. Median hair, fingernails and toenails levels (µg/g) were also elevated, particularly for Hg.

PO4.8. Occupational and environmental exposure to Mn in manganese mining areas (South Portugal) and the occurrence of dementia

CABRAL PINOTI Marina, ALMEIDA Agostinho, PINOTI Edgar, FREITAS Sandra, SIMÕES Mário, DINIZ Luisa, MOREIRA Paula, SILVA Maria, FERREIRA DA SILVA Eduardo, SILVA LOUREIRO Maria, CONDESSO De MELO M. Teresa

Occupational and environmental exposure to manganese (Mn) has been suggested as a possible cause of neurodegenerative disorders. The inhalation and ingestion of Mn affects the central nervous system of mammals, particularly of humans. Various cases have been reported of neurological pathologies, and even deaths, induced by chronic consumption of water containing moderate to high levels of Mn (median values in groundwaters > 81.2 µg/L well above drinking water limits and > 171 mg/L in surface waters affected by acid mine drainage). In Baixo Alentejo region (South Portugal) there are several abandoned Mn mines, related with the Fe-Cu-Zn-Pb massive sulphides deposits, and close to the mines there are abandoned tailings deposits, freely exposed to weathering, rich in metal(loid)s such as Cu, Pb, Zn, As, Sb, Ag, Hg and Cd. The concentration of these metal(loid)s is being determined in soil, water and plants of target and control areas. Inhabitants were assessed by cognitive screening tests, for early detection of dementia. The following instruments were administered to each participant: 1) a complete socio-demographic questionnaire; 2) General Health Questionnaire; 3) Mini Mental State Examination; 4) Montreal Cognitive Assessment; 5) Clinical Dementia Rating scale; 6) Geriatric Depression Scale; 7) Recall Selective Free and Guided Test. The neuropsychological assessment of a pre-selected population in the studied areas is being investigated and correlated to the content of selected metal(loid)s on human biological samples (nails, hair, blood and urine). The environmental exposed inhabitants of this study has proved to consist mainly of subjects with Mild Cognitive Impairment (MCI) (36%), followed by normal subjects (34%) and subjects with dementia (30%). Maximum fingernails Mn level (1.43 µg/g) was found in a subject with Parkinson dementia, however the maximum toenails Mn level (1.38 µg/g) was found in subjects with MCI. Median fingernails levels (µg/g) were elevated for Hg, particularly in subjects with dementia (0.8), and also in MCI (0.6).

PO4.10. Personal image and self in dementia: The perspective of the caregiver spouse

VODUŠEK Vid Vanja

“Self” and “identity” are conceived as essentially dissociable in the critical literature of the psychosocial approach to dementia: “self” is understood as a bare function of self-reference, “identity” as a set of different social roles which make up the content of this self-reference. On the basis of this dissociation, the authors of the critical approach argue that a person can lose a part of her identity by way of memory loss, but because the self-referential function remains intact, she can still participate in most communication situations: thus she can still coherently communicate the remaining parts of her identity, and through communication replace the ones that are missing. I argue that the self is essentially based in the social roles and perspectives an individual can assume: if a social perspective is lost, so is the ability to communicate from that perspective. To identify the behaviours and situations through which we can delineate the main structural change determinants of the self in persons with dementia, I have conducted two focus groups and 9 intensive interviews with caregiver spouses. By way of grounded theory I have shown how psychological dependency of persons with dementia increases in the course of the illness and how these persons lose their bearings in communication situations of the broader social context, whereas they are still competent communicators in their circle of friends and relatives. I conclude that the self of the demented person becomes increasingly structurally dependent on the interactions with significant others, and that the self’s repertory of perspectives is narrowed in the direction of the core repertory of significant others’ perspectives.

PO4.11. Cognitive and behavioural changes in patients with ALS - implications for treatment and disease management

ŠTUKOVNIK Vita

Traditionally, amyotrophic lateral sclerosis (ALS) has been viewed as a disease of the motor system, characterized by degeneration of both the upper and lower motor neurons, with no compromise of cognitive and behavioural functions. However, latest research provides evidence of extra-motor involvement in this disease. Studies suggest that up to 50% of patients with ALS demonstrate mild to moderate cognitive and/or behavioural impairment and that up to 20% of patients with ALS meet criteria for full-blown dementia syndrome. Deficits are characterised by executive and working-memory impairments, extending to changes in language and social cognition. Behaviour...
and social cognition abnormalities are closely similar to those reported in behavioural variant frontotemporal dementia, implying a clinical spectrum linking ALS and frontotemporal dementia (FTD). Despite the increased awareness of ALS as a multi-system disorder, the cognitive status of most ALS patients attending clinics remains unknown. Standard assessment procedures are often not appropriate to detect dysfunction due to progressive physical disability of patients. A new screening instrument was recently developed to detect the specific profile of cognition and behaviour changes in ALS (Edinburgh Cognitive and Behavioural ALS Screen, ECAS) and is currently being standardized in Slovenian language. Accurate assessment of cognitive and behavioural symptoms in ALS is crucial not only in the light of therapeutic trials, but also to the planning of care, compliance to interventions and end-of-life decisions. It was shown that patients with ALS–FTD are much more likely to be noncompliant with clinical interventions to improve their quality of life, such as non-invasive ventilation and occupational/physical therapy. The issue of cognitive (in)dependency may also be an important issue for ALS caregivers, whose burden was found to be even greater, when taking care of patients with cognitive impairment. As most people with ALS are cared for at home, more insight into patients’ cognitive status and support in symptom management might be crucial to provide a better quality of life for both patients and their caregivers.

PO4.12. Sequence of cognitive decline in Alzheimer’s Disease (AD) patients - results from an observational study

DELL’AGNELLO Grazia, HENNEGES Carsten, REED Catherine, CHEN Yun Fei, LEBREC Jeremie

Introduction: Understanding the pattern of decline in cognitive functioning in Alzheimer’s disease (AD) could assist primary care physicians in explaining AD progression to patients and caregivers. The objective of this analysis is to determine if there is an identifiable order in which cognitive abilities are lost within the progression of AD.

Methods: CERAS is an 18-month observational study on AD. Patients diagnosed with probable AD and Mini Mental State Examination (MMSE) ≤26 were enrolled. Proportional odds logistic regression model was applied to model MMSE subscales of orientation, registration, attention and concentration (spelling and counting), word recall, language and copying. The model converted ordinal scores of each subscale to corresponding probabilities of cognitive impairment at each MMSE total score level where the probabilities were estimated based on start of and complete cognitive impairment.

Results: 1495 patients were analyzed. Figure 1 shows the probability estimates of start of complete cognitive impairment. The first aspect of cognition to become impaired is word recall, followed by orientation in time. The last abilities to fully deteriorate are orientation in place, language, and registration.

Conclusions: The process of cognitive decline was visualized by means of probability estimates of key aspects of cognition. This might be useful to set expectations on disease progression for patients/caregivers.

PO4.14. Factors underlying adherence to transdermal therapy in Alzheimer’s dementia

KNOX Sean, RIEPE Matthias, WEINMAN John, MULICK Cassidy Amy, CHAVES Ricardo, MUELLER Beate

Background: Poor adherence to prescribed treatments is a major barrier in the care of patients with Alzheimer’s Disease (AD). To effectively manage AD and maximise therapeutic efficacy, adherence to treatment is paramount.

Objectives: The study was aimed to identify patient and caregiver-related factors influencing adherence to transdermal therapy.

Methods: Patients with mild-to-moderate AD prescribed transdermal therapy in 18 centres across Germany were included in this study. Socio-demographic, clinical and psychosocial data about patients and their caregivers were collected at 3 months after treatment.
initiation (Visit 1; n=127). Standardised questionnaires were used to assess factors associated with adherence to transdermal therapy and treatment satisfaction at 3 and 6 months (Visit 2; n=110) post initiation of medication. Predictors of adherence were identified using stepwise linear regression models.

Results: At the second-follow up visit, 66.2% of caregivers reported being adherent and 72.0% were satisfied with the transdermal therapy. Higher adherence to transdermal therapy chiefly correlated with higher caregiver satisfaction with information on medication and patients’ better tolerability to therapy (both p<0.001). Caregiver contact of ≤3 hours per day or once/twice per week, patients living at home alone, greater caregivers’ concerns about transdermal therapy and patient belief in ‘other’ causes of their AD predicted lower adherence (all p<0.03).

Conclusions: Patient living conditions, frequency of caregivers’ visits, adherence (all p<0.03).

PO4.15. Whole-body cryostimulation as possible prevention of cognitive deterioration

SZCZEŃIAK Dorota, URBANSKA Katarzyna, TRYPIKA Elżbieta, STANCZYKIEWICZ Bartłomiej, RYMASZEWSKA Joanna

Background: Limitations of currently available treatment methods of dementia imply constant need to search for new, supplementary therapy strategies. Hypothesis of translating whole-body cryostimulation in psychogeriatric field is pointed out despite the fact that there were no research studies addressed the impact of extremely low temperatures on the cognitive functions. The possible biological mechanisms can be based on already improved anti-inflammatory (a modification of the concentration of proinflammatory cytokines) and antioxidative effect of extremely low temperatures on human body as well as the hormonal and lipid changes they cause. Our aim was to assess the influence of whole-body cryostimulation on cognitive functions as well as on mood and quality of life of patients with MCI.

Methods: The RCT design is used divided patients (over 55 yrs.) with MCI into two groups (1) experimental: -110°C till -160°C, 2-3 minutes each day and (2) placebo: -20°C, 2-3 minutes each day undergo 10 sessions of WBCT. The cognitive functions (CDR, MoCA, TYM, DemTect, SLUMS), quality of life (WHOQOL – BREF), depressive symptoms (HAM-D) and biochemical parameters are measured at baseline and in follow-up.

Results: We hypothesize that whole-body cryostimulation will significantly improved the cognitive functions and quality of life. Moreover the worse the cognitive deficits of the patients were prior to the cryotherapy, the stronger its effect in comparison to the control group. The results of currently conducted study will be presented during the conference.

Discussion: Short, intense series of whole body cryo-stimulation could be recognized as the complementary prevention and treatment method of the early stages of cognitive impairments leading to dementia.

PO4.16. Effect of early care recourse to specialist in dementia on institutionalization and functional decline: findings from a population-based study

PIMOUGUET Clément, LE-GOFF Mélanie, BERR Claudine, DARTIGUES Jean François, HELMER Catherine

Objectives: To investigate the influence of early specialist consultation for dementia on institutionalization and functional decline in Activity of Daily Living (ADL).

Design: Prospective longitudinal cohort

Setting: Population-based study (the 3C study)

Participants: Non-institutionalized incident dementia participants (n=179) for institutionalization; Non-institutionalized incident dementia participants who were free of ADL disability (n=243) for functional decline.

Main outcomes measures: Incidence of institutionalization and rate of ADL dependency for dementia participants who had an early specialist consultation in comparison with those who did not.

Results: Only one third of the incident demented individuals had consulted early a specialist for cognitive problems (36%). After adjustment on potential confounders and competing risk of death, participants who had consulted a specialist early in the disease course presented a higher rate of being institutionalized than those who did not (Subdistribution Hazard Ratio = 1.98, 95% Confidence Interval 1.11-3.55). Specialist recourse was not associated with further functional decline (Hazard Ratio = 1.09, 95% CI 1.71-1.67).

Conclusions: Early specialist recourse in dementia is associated with increased risk of institutionalization but not with functional decline in ADL. These findings suggest that early care recourse in dementia may be a marker of concern for patients and/or caregivers; subsequent medical and social care could be suboptimal or inappropriate in order to allow patients to stay longer at home.

PO4.17. Risk factors for development of dementia: the Prospective Epidemiologic Risk Factor (PERF) I study

NEERGAARD Jesper S., DRAGSBÆK Katrine, HANSEN Henrik B., HENRIKSEN Kim, CHRISTIANSEN Claus, KARSDAL Morten A.

Objective: Despite the extensive research effort, the list of putative risk factors in relation to dementia is still inadequate to confidently assess their association with disease. It is not yet clear whether the results of the previous studies are of sufficient strength to warrant specific recommendations for disease treatment and/or prevention. In the present study we assessed the incidence and identified risk factors for development of dementia in the largest individual prospective cohort

KARSDAL Morten A.
of elderly women.

Methods: The Prospective Epidemiologic Risk Factor (PERF I) study, an observational, prospective follow-up study of Danish women, was conducted between 1999 and 2001 (n=5,855). Follow-up information was retrieved from the national Danish registries. A Cox proportional hazards regression model was applied to calculate adjusted hazard ratios (HR) for potential risk factors.

Results: Of 5,840 eligible subjects, 582 developed dementia after 15 years of follow up, leading to an overall incidence of 8.3 per 1000 person years. The incidence approximately doubled every 5 year starting at the age of 60.

Depression was associated with increased risk of dementia (HR = 2.18 [95% CI 1.59-2.98]). A dose-response relation was observed with fasting plasma glucose leading hazard ratios of 1.37 [1.13-1.66] and 1.50 [1.00-2.25] for impaired (≥6.6-9 mmol/L) and hyperglycemic (≥7.0 mmol/L) fasting glucose levels, respectively. Overweight (BMI 25-29.9) and physical activity (≥1 time/week) was negatively associated with risk of dementia leading to hazard ratios of 0.69 [0.56-0.85] and 0.73 [0.61-0.86], respectively.

Interpretation: We confirm some of the most widely studied risk factors for dementia in the largest individual cohort of elderly women.

PO4.18. Avoidable hospitalizations in incipient dementia

PIMOGUET Clément, RIZZUTO Debora, LACERGREN Marten, FRATIGLIONI Laura, XU Weili

Objectives: To determine whether avoidable and all-cause hospitalizations are associated with incipient dementia.

Design: Prospective longitudinal cohort of 2240 dementia-free participants aged 60+ years and followed-up to 6 years.

Setting: The Swedish National Study on Aging and Care in Kungsholmen (SNAC-K).

Methods: Avoidable hospitalizations and all-cause hospitalizations were tracked through the inpatient register. Avoidable hospitalization was defined by a hospitalisation for any ambulatory care-sensitive condition as categorised by the National Board of Health and Welfare and Swedish Association of Local Authorities and Regions. All-cause hospitalization was defined as any hospitalization requiring an overnight stay. Dementia was diagnosed following DSM-IV criteria at baseline and at the first follow-up. Rates of hospitalizations occurring over the period between baseline and the first follow-up were compared between participants who developed dementia at the first follow-up (incipient dementia) and those who remained free of dementia. Zero inflated Poisson regression models were used to analyze hospitalizations rates. Case/control analyses were performed after matching on age, gender and chronic diseases in order to test the robustness of the findings.

Results: Of all dementia-free participants, 158 participants developed dementia at the first follow-up. Avoidable hospitalization was associated with incipient dementia (odds ratio (OR) =2.67, 95% CI: 1.2-6.45) after controlling for potential confounders including comorbidities, cognitive and functional disability at baseline.

Conclusion: Avoidable hospitalization is associated with incipient dementia. Our findings suggest that primary care for elderly people with incipient dementia is suboptimal. They argue in favor more systematic cognitive screening and subsequent clinical monitoring in primary care.

PO4.21. Zdravljenje demence

LAH Samira

Zaradi staranja populacije je demenca pojav, katerega pojavnost hitro narašča in ne prizadene le posameznikov in njihovih svojcev, pač pa zadeva tudi širšo družbo. Ob takšni naraščajoči pojavnosti menimo, da je ključna tudi njena preventiva. Študije, ki raziskujejo rizične dejavnike za demenco, so si nemalokrat nasprotujoče, a kljub temu številne raziskave nakazujejo, da obstajajo pomembni rizični dejavniki, na katere imamo kot posamezni vpliv, da delujemo preventivno.

Namen našega prispevka je osvetoiti nekatere preventivne aktivnosti, ki po našem mnenju pripomorejo k zmanjševanju oziroma upočasnjevanju dejavnikov tveganja za razvoj bolezni.

Osnovno izhodišče, ki ga zavzemamo pri intervencijah, je približati terapevtske učinke posameznih aktivnosti skozi igro, ki povezuje različne vrste učenja: socialno, čustveno, miselno, govorno, jezikovno, motorike in koordinacije oko – roka (vaje za spodbujanje ravnovesja, gibljivosti, ročne spretnosti); kognitivne vaje (spomin, pozornost, koncentracija); socialne veščine (pripomorejo, da je posameznik čim daje časa aktiven na področju komunikacije in druženja z ljudmi); krepitev zdravega življenjskega stila in skrb za zdravo prehrano.

Z aktivnostmi želimo posameznikom ponuditi možnost za socialni
PO4.22. Tehnološka podpora pri oskrbi ljudi z demenco v skupnosti
MALI Jana, ŽITEK Nina

Demence postaja v življenju sodobnega človeka vedno bolj prepoznaven pojav. Po novejših strokovnih spoznanjih predstavlja demenca tudi možnosti in priložnosti za nove življenjske izide. V središču pozornosti ni demenca, temveč človek, ki ima demenco in za samostojno življenje potrebuje veliko podpore. Predstaviti želimo projekt, katerega namen je razviti takšne rešitve za ljudi z demenco v njihovem domačem okolju, ki izhajajo iz potreb ljudi z demenco in z uporabo informacijsko-komunikacijske tehnologije prispevajo k krepitvi moči ljudi z demenco. V projektu študentje Fakultete za socialno delo in Fakultete za elektrotehniko sodelujejo z Zavodom za oskrbo na domu Ljubljana in podjetjem ComSensus. Sodelovanje omogoča razvoj pomoči, ki temelji na interdisciplinarnem sodelovanju in zagotavlja oskrbo v domačem okolju. Iskanje sodobnih tehnoloških rešitev temelji na potrebah ljudi z demenco, izhaja iz njihovih življenjskih razmer, stopnje demence, s ciljem odpravljanja konkretnih ovir in tveganj v vsakdanjem življenju. Projekt z interdisciplinarnim iskanjem rešitev in s participacijo ljudi z demenco na inovativen način prispeva k razvoju kakovostne oskrbe v domačem okolju ljudi z demenco. Projekt je inovativen v zagotavljanju interdisciplinarnega povezovanja študentov in strokovnjakov iz prakse, omogoča pa tudi sodelovanje obeh mentorjev na fakultetah. Inovativna je pristop do ljudi z demenco, njihovo neposredno vključevanje pri razvijanju rešitev kar še ni uveljavljen način praktičnega delovanja pri nas. Prav tako pri nas ujemanje tehnoloških rešitev v vsakdanje življenje starih ljudi še ni učena praksa, poznamo pa jo v tujini. Povezovanje socialnih vidikov demence in tehnoloških rešitev za ljudi z demenco je inovacija tudi na nacionalni ravni. Inovativna je tudi aktivna vloga študentov pri iskanju konkretnih izboljšav v življenju ljudi z demenco. Glede na aktualnost projekta pričakujemo, da bodo izkazane rešitve uporabno vrednost za dvig kvalitete življenja ljudi z demenco v domačem okolju.

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Mark the dates!

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