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INTERNATIONAL  
PSYCHOGERIATRIC  
ASSOCIATION

555 East Wells Street, Suite 1100

Milwaukee, WI 53202

United States

Ph: +1 414 918 9889

Fx: +1 414 276 3349

info@ipa-online.org

http://www.ipa-online.org/

## PRESIDENT'S MESSAGE – MANABU IKEDA

Dear Colleagues,

After the last couple of years of postponements and shifting to virtual, we are pleased to finally be hosting the IPA International Congress in Lisbon (June 29 – July 2, 2023). I am delighted to welcome colleagues and IPA members worldwide to this congress.



The scientific program showcases the latest findings in psychogeriatrics and mental health research for older adults. We are keen to enable participation by early career researchers in our field and are delighted that many of them will have an opportunity to present their research results and attend the ECN program. There will be 210 poster presentations, and 41 Free/Oral presentations have been selected. In addition, the 5 Plenary sessions, 22 Symposia sessions, and 6 Pre-Congress Workshops will provide exciting and valuable information for clinicians and researchers. We encourage you to connect with your colleagues at special events such as the Welcome Reception/Cocktail Hour and Long Term Care Site Visits. We hope these events will be enjoyable and facilitate scientific collaborations and international friendships.

Thank you for supporting IPA and this year's International Congress!

With Kindest Regards,

Dr. Manabu Ikeda

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### EDITOR'S NOTE — TZUNG-JENG HWANG

June is an exciting moment when IPA will convene an international congress. In this issue, our president, Prof. Manabu Ikeda, has shared with us the content of the congress program, including 5 Plenary sessions, 22 Symposia sessions, 6 Pre-Congress Workshops, etc. **After a long COVID pandemic, we are thrilled to meet many IPA members and colleagues worldwide in Lisbon, where we can share experiences and have fun together.**



In the **“International Psychogeriatrics Review Column”**, Dr. Jiaming Liang (USA) Reviews the paper “Pharmacological and nonpharmacological approaches to reduce disinhibited behaviors in dementia: a systematic review” by Burley, Burns, and Brodaty (2022). The systematic review shows that effective interventions include pain management, antidepressants, models of care, education and/or training, music-based approaches, and physical activity. Both pharmacological and nonpharmacological intervention studies have high overall research quality, while the mean effect size of RCT nonpharmacological interventions is larger than pharmacological approaches.

There are 3 articles in **“Research and Practice”**, and 3 in **“Around the World”**. In **“Research and Practice”**, Dr. Rita Khoury (Lebanon) reviews depression, anxiety, post-traumatic stress disorder (PTSD), and cognitive impairment in Lebanese patients on hemodialysis. She found patients on hemodialysis are at increased risk for depression, anxiety, PTSD, and cognitive impairment. Drs. Michael Kob and Laura Valzolgher (Italy) report eating disorders in dementia. They show that eating disorders are part of the neuropsychiatric symptoms of dementia, with the presentation according to the type of dementia. In frontotemporal dementia, neurodegeneration could impair the signaling to the hypothalamus and the satiety response. Dr. Sil Aarts (the Netherlands) describes the importance of data-informed decision making in long-term care for older adults, especially in long-term care organizations, which provide care for some of the most vulnerable in society.

In **“Around the World”**, Dr. Joan Ostaszkievicz (Australia) reports how and why a research team from the [National Ageing Research Institute](#) (NARI), in collaboration with [Deakin FutureLearn](#) in Australia, designed and disseminated a Massive Open Online Course (MOOC) on **‘Caregiving, Dementia and Incontinence’**, which is available from anywhere in the world. Dr. Guangwei Ji et al. (China) describe their effort to explore an innovative palliative care model in rural China, where the deeply rooted influence of traditional opinions toward life and death hinder the development and dissemination of palliative care. Finally, Dr. Javier Vicente-Alba

EDITOR'S NOTE, *continued on next page*

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(Spain) shares the development of a mental health team in Pontevedra (Galicia, Spain), which provides a socio-healthcare to institutionalised patients.

It is fascinating to know what is happening around the world and what are new innovations in psychogeriatric research and service. The *IPA Bulletin* editorial team cordially invites you to contribute your thoughts and experiences to the *Bulletin*! You can reach us at [ipa.b.editor@gmail.com](mailto:ipa.b.editor@gmail.com).

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# 2023 IPA International Congress

## Lisbon, Portugal • June 29-July 2, 2023

Congress program: <https://www.ipa-online.org/events/2023/program>

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### Keynote & Plenary Speakers



**Amal Abou Rafeh, United States**

*Emerging Concepts in Combating Ageism, Protecting and Promoting Human Rights and Mental Health of Older Persons*

Thursday, 29 June 5:30pm – 7:00pm  
Main Auditorium



**Rose-Marie Dröes, The Netherlands**

*The importance and value of psychosocial care in dementia in historical perspective, with reflection and commentary*

Saturday, 1 July 9:00am – 10:00am  
Main Auditorium



**Claudia Mahler, Switzerland**

*Emerging Concepts in Combating Ageism, Protecting and Promoting Human Rights and Mental Health of Older Persons*

Thursday, 29 June 5:30pm – 7:00pm  
Main Auditorium



**Masaru Mimura, Japan**

*Disease-Modified Drug*

Saturday, 1 July 3:40pm – 4:40pm  
Main Auditorium



**John Beard, United States**

*Healthy Ageing and the role of physical and social environments*

Friday, 30 June 9:00am – 10:00am  
Main Auditorium



**Marjolein de Vugt, The Netherlands**

*The role of social connectedness in multifactorial demential syndrome. Does social life matter? - IPA/INTERDEM webinar*

Sunday, 2 July 9:00am – 10:00am  
Main Auditorium



**Dilip Jeste, United States**

*Late onset psychosis / schizophrenia*

Friday, 30 June 5:00pm – 6:00pm  
Main Auditorium



**Sube Banerjee, United Kingdom**

*The role of social connectedness in multifactorial demential syndrome. Does social life matter? - IPA/INTERDEM webinar*

Sunday, 2 July 9:00am – 10:00am  
Main Auditorium



**Manabu Ikeda, Japan**

*Late onset psychosis / schizophrenia*

Friday, 30 June 5:00pm – 6:00pm  
Main Auditorium



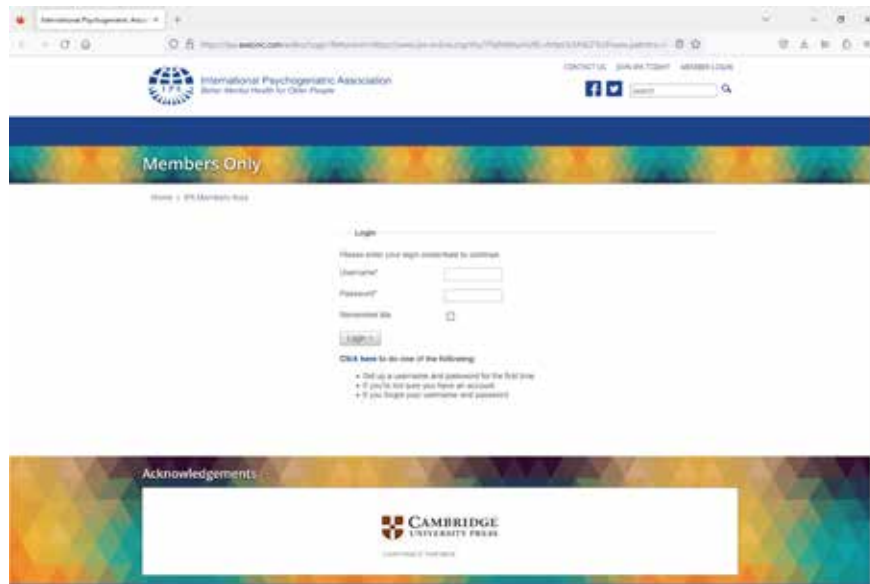
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*President-Elect Closing Remarks*

Sunday, 2 July 2:30pm – 3:00pm  
Main Auditorium

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## REVIEW OF “PHARMACOLOGICAL AND NONPHARMACOLOGICAL APPROACHES TO REDUCE DISINHIBITED BEHAVIORS IN DEMENTIA: A SYSTEMATIC REVIEW” BY BURLEY, BURNS, AND BRODATY (2022)

Jiaming Liang

University of Southern California, CA, USA

### Key highlights

- Among the 30 included studies (9 pharmacological and 21 non-pharmacological), only 14 (7 pharmacological and 7 non-pharmacological) reported significant decreases in disinhibited behaviors. Effective intervention approaches include pain management, antidepressants, models of care, education and/or training, music-based approaches, and physical activity.
- Both pharmacological and non-pharmacological intervention studies have high overall research quality, while the mean effect size of RCT non-pharmacological interventions is larger compared to pharmacological approaches (mean Cohen's  $d = 0.49$  and  $0.27$ , respectively).
- Some factors that may improve effects of reviewed studies include adopting a consistent and comprehensive definition of disinhibited behaviors, RCT design, larger sample sizes, comprehensive assessment tools with gold standards, and consideration of demographic, health, social and cultural characteristics of PLWD.

Older people living with dementia (PLWD) commonly experience changes in affect, cognition, and behavior. Behavioral and psychological symptoms of dementia (BPSD), which encompass a heterogeneous group of non-cognitive symptoms and behaviors, is the term to describe the multifaceted changes experienced by PLWD (Finkel et al., 1997). Some of the BPSD may cause difficulties for PLWD's independent living, increase the care burden of families, and may result in more serious social repercussions (Guimet et al., 2021). Therefore, investigating the physiological and phenomenological mechanisms underlying the various BPSD change patterns can help healthcare providers and families better understand the health status of PLWD, and inform the development of interventions aimed at preventing exacerbations of BPSD while also improving the coping capacity of caregivers.

Disinhibited behaviors are one of the behavioral symptoms commonly experienced by PLWD. Specifically, PLWD may exhibit some “socially inappropriate behaviors”, such as impulsive aggression, substance abuse, and inappropriate sexual behaviors (Alkhalil et al., 2004; Halloran, 2014; Miller et al., 1997). However, the lack of agreement on the

pathological origin and underlying mechanisms in existing research impedes the development of related treatments and interventions. According to Burley et al. (2022), the definitions of disinhibited behaviors are inconsistent on whether to include emotional, psychological, and sexual aspects, which likely explains the variable prevalence rates of disinhibited behaviors reported in the literature. In addition, there is debate regarding the physiological mechanism of disinhibited behaviors, such as “impulse suppression disability” versus “hyperactivity”, which largely determines the progress of pharmacological interventions. Furthermore, the appropriateness of PLWD's behavior may vary in different social, cultural, or religious contexts, which also affects the external validity of behavioral interventions (Guimet et al., 2021). Accordingly, it is necessary to systematically review the existing treatments and interventions for disinhibited behaviors of PLWD, in order to describe their effects and reveal areas for future clinical and research endeavors.

Burley et al. (2022) adopted a rigorous methodology to increase the accuracy and credibility of the review results in light of the aforementioned challenges. To address inconsistencies in the definitions of disinhibited behaviors

PHARMACOLOGICAL AND NONPHARMACOLOGICAL APPROACHES TO REDUCE DISINHIBITED BEHAVIORS IN DEMENTIA, *continued on next page*



across studies, they employed a thorough search strategy that included studies on verbal behaviors, sexuality, emotion, and general BPSD. The approach builds on a prior attempts to distinguish between physiological and psycho-behavior-based strategies by categorizing interventions into pharmacological and non-pharmacological categories. To guarantee the statistical and clinical significance of the results, the review also employs structured tools to assess the research quality of included studies based on study design, participant characteristics, outcome measures, and statistical analyses. Standardized effect sizes were also calculated for randomized controlled trials (RCT). The overall methodology satisfies the requirements of the mainstream systematic review quality appraisal framework (i.e., AMSTAR-2) (Shea et al., 2017).

For this systematic review, 30 studies on disinhibited behavior interventions in PLWD were identified, including 9 pharmacological and 21 non-pharmacological interventions. The included studies came from 15 countries, and more than half were conducted in Europe. It is important to note that all these studies treated disinhibited behaviors as secondary outcomes. The Neuropsychiatric Inventory (NPI) disinhibition subscale was used in 26 of the included studies, and other studies used relevant subscales from the Frontal Behavioral Inventory (FBI) and Cohen-Mansfield Agitation Inventory (CMAI). Among the 9 pharmacological interventions, 3 used RCT design, and 7 studies with a total of 2,825 participants reported significant results which indicated that pain management, antidepressants, or traditional herbal medications (e.g., risperidone, citalopram, and yokukansan) can reduce disinhibited behaviors. Although the overall research quality was strong and the 3 RCTs showed small to medium effect sizes (mean Cohen's  $d = 0.27$ ), these studies still have design limitations like small sample sizes, no follow-up, and lack of control/placebo groups.

Among the 21 non-pharmacological interventions, 14 used RCT design, and only 7 had enough data to calculate effect sizes. Seven effective studies (including 4 RCTs) adopted various intervention approaches, including 3 care models,

2 staff education and training programs, 1 music therapy program, and 1 physical activity intervention. Communities, residential care facilities, and dementia-specific care units were among the research settings. Non-pharmacological interventions had comparably strong research quality to pharmacological interventions, but their mean effect size was larger (Cohen's  $d = 0.49$ ). Models of care and educational training programs exhibited the greatest disinhibited behaviors reduction and the largest study effect sizes. These studies share the following three characteristics: First, they are individualized programs that comprehensively assess participants' health status (e.g., BPSD, medications, daily behaviors); Second, they all involve different stakeholders (i.e., family caregivers, nursing staff, psychologists, and physicians) in the development of treatment or training plans; Third, they all have regular effect evaluations to ensure the quality of the interventions. These three characteristics guarantee the effects of interventions and give future interventions a methodological framework.

This systematic review found inconsistent results of existing interventions for reducing PLWD's disinhibited behaviors. Only 14 of the 30 included studies presented statistically significant findings. Effective studies showed that non-pharmacological interventions have a larger mean effect size than pharmacological interventions, particularly when they employ approaches like models of care and educational training; the person-centered approaches can provide PLWD and their families with creative individualized solutions. Factors dampening the intervention effects include lacking consistent and comprehensive definitions of disinhibited behaviors, RCT design, large samples, comprehensive assessment tools with gold standards, and consideration of the demographic, health, social and cultural characteristics of PLWD.

The results of this systematic review can inform future research. For intervention studies, disinhibited behaviors should be examined specifically and comprehensively as primary outcomes. Although many studies used the disinhibition subscale of NPI as an outcome measure and

adapted it for groups of different genders, races, languages, and dementia subtypes, the subscale only assesses hyperactivity rather than the loss of impulse control. Sexual disinhibition was not assessed either. Research should also adopt more rigorous designs, such as using RCT to set control/placebo groups and improve the effectiveness of interventions. For clinical practice, patient-centered non-pharmacological strategies respect the rights of PLWD to the greatest extent, promote communication between healthcare providers and PLWD's families, and caregivers, and avoid /minimize drug toxicity and adverse effects. It is suggested that drug therapy should be reserved for use when nonpharmacological strategies have failed, and then only if necessary in the short term.

As this systematic review only includes articles published in English, and most of the included studies come from developed regions like Europe and North America, the representativeness of the results for disinhibited behavior interventions in developing countries is questionable. Future research should pay more attention to the implementation of disinhibited behavior interventions in low- and middle-income countries, and present practice solutions to health disparities facing local PLWD populations.

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Dr. Jiaming Liang is a Provost post-doctoral research fellow affiliated with the Alzheimer Disease Research Center (ADRC) and the Suzanne Dworak-Peck School of Social Work (SDP-SSW) at the University of Southern California (USC).

His research focuses on supporting older adults living with cognitive impairment or dementias and their family caregivers, as well as their experience of accessing and utilizing community-based social and health services.



### DEPRESSION, ANXIETY, PTSD, AND COGNITIVE IMPAIRMENT IN LEBANESE PATIENTS ON HEMODIALYSIS: A CALL FOR ACTION

Rita Khoury, MD

American University of Beirut, Faculty of Medicine and the Medical Center, Beirut, Lebanon

#### Key highlights

- Patients on hemodialysis are at increased risk for depression, anxiety and post-traumatic stress disorder (PTSD).
- Patients on hemodialysis, particularly older adults, are at increased risk of developing cognitive impairment, due to cardiovascular risk factors and psychiatric comorbidity.
- Physicians should perform a brief psychiatric and cognitive screening prior to starting hemodialysis and during dialysis, especially in the context of recent trauma.
- In a cross-sectional study involving 42 Lebanese participants on hemodialysis who were subject to a major trauma (Beirut explosion), prevalence rates of depression, anxiety, PTSD, and cognitive impairment were alarming at 57.1%, 54.8%, 33.3% and 23.8% respectively, necessitating urgent interventions in this population.

Cognitive impairment is common and often undiagnosed in patients on hemodialysis, due to older age and increased cardiovascular comorbidities, notably the presence of strokes (1). It can also be exacerbated by the increased risk of having comorbid psychiatric illness, including depression, anxiety, suicidal ideations and post-traumatic stress disorder (PTSD) (2). The prevalence of cognitive impairment among patients on hemodialysis, assessed using neuropsychological tests, varies from 16 to 38%, whereas this prevalence ranges from 6.6 to 51%, using screening tests. The most commonly used screening tests were the Mini-Mental State Examination (MMSE), the Montreal Cognitive Assessment (MoCA) and the Modified Mini-Mental State (3MS) (3).

On August 4, 2020, Beirut, the capital city of Lebanon which is a small Mediterranean, low-income country, witnessed a major explosion resulting in more than 200 deaths and 7000 injured (4). Several hospitals were either partially or completely destroyed, and many hospital staff and patients were injured or killed by the blast, including patients undergoing hemodialysis.

In this context, we conducted a cross-sectional study between March and April of 2021 (6 months following the disaster) to explore prevalence rates of depression, anxiety,

suicidal ideations, PTSD, and cognitive impairment among adults receiving hemodialysis at Saint Georges Hospital University Medical Center, which is a major hospital that was destroyed by the blast. The Hospital Anxiety and Depression Scale (HADS) was used to assess for anxiety and depression using cut-offs of  $\geq 6$  and 7 for anxiety and depression, respectively (these cut-offs have been commonly used in the population of hemodialysis subjects) (5). Suicidality was assessed using direct questioning about passive death wishes, ideations, plans or attempts. PTSD was assessed using the PTSD checklist for DSM-5 (PCL-5), which is a 20-item screener based on the Diagnostic and Statistical Manual (DMS)-5 criteria for PTSD. A cut-off of 23 was used, which is based on a previous study in Arab refugees (6). Cognitive impairment was assessed using the Mini-cog which is comprised of word-recall and clock drawing components and has a sensitivity of 80 to 99%, and a specificity of 90 to 93% (7, 8); this tool has not been used in the literature before in patients undergoing hemodialysis.

A total of 42 patients were included in the assessment. Mean age of participants was 66.1 years with a standard deviation (SD) of 11.3. 92.9% of the participants were age 50 years or older. 45.2% were females. 31% had a high-school-

level education or above. 66.7% belonged to a middle socioeconomic status (SES) and 9.5% to a high SES.

Anxiety and depression rates were found to be high, reaching 54.8% and 57.1%, respectively. 26.2% had passive death wishes and 7.1% had suicide plans; however no one had attempted suicide. 33.3% screened positively for PTSD using the PCL-5. Around a quarter of the sample (23.8%) were found cognitively impaired as shown by the Mini-Cog (<3), despite no previous dementia diagnosis. The data is presented in the figure below.

Our study showed significantly higher rates of anxiety and depression (55 and 57%, respectively), compared to patients undergoing hemodialysis in other Lebanese hospitals prior to the blast using the same screening instrument, the HADS (9, 10); these rates are also among the highest in the Arab world, notably in comparison to Saudi Arabia, Morocco, and Kuwait (11-14).

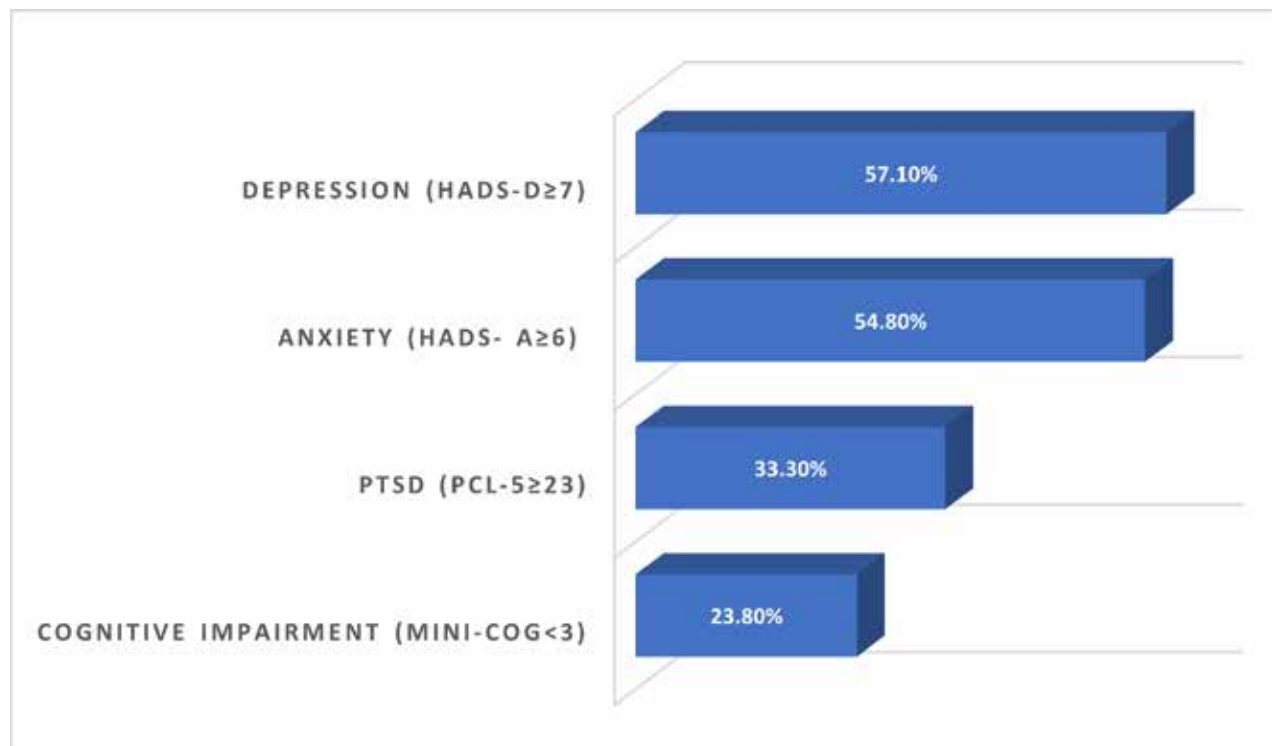
Our study is the first to explore PTSD and cognitive impairment prevalence rates in patients on hemodialysis

in Lebanon and the Arab countries. The respective rates of 33.3 and 23.8% were found to be alarming, and higher than international figures, even after major traumatic events. For instance, in the year following hurricane Katrina in New Orleans, United States, 23.8% of hemodialysis patients reported symptoms consistent with PTSD using the PCL-17/ DSM-IV (15).

It is noteworthy that the population has been going through several cumulating stressful factors in addition to the Beirut blast. In October of 2019, there was an enormous devaluation of Lebanese currency, and this was followed by the COVID-19 pandemic, which has been perceived as a traumatic event by itself, especially in a vulnerable population like older adults on hemodialysis.

This population needs particular attention with respect to their mental health, as it is directly correlated with quality of life and mortality risk. Regular screenings prior to initiation and during hemodialysis are needed to improve early detection and management of these disorders.

**Figure 1. Screening for Psychiatric Disorders in Lebanese Hemodialysis Patients (N=42)**



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### EATING DISORDERS IN DEMENTIA: BINGE EATING IN FRONTOTEMPORAL DEMENTIA (FTD)

Michael Kob MD, Laura Valzolgher MD  
Hospital of Bolzano, Italy

#### Key highlights

- eating disorders are part of the neuropsychological symptoms of dementia, they have presentation according to the type of dementia and increasing frequency in the later course of the disease
- the neurobiology of food intake regulation is believed to have 2 pathways: a homeostatic and a hedonistic mechanism involving different brain regions: hypothalamus, limbic system, cortical regions
- in frontotemporal dementia neurodegeneration in these areas could impair the signaling to the hypothalamus and the response to satiety
- in frontotemporal dementia, eating disorders such as binge eating and bulimia, are distinctive features of the disease (especially in the behavioral variant) that are associated with important burden and require a pharmacological approach

#### INTRODUCTION

Eating disorders are listed among the behavioral and psychological symptoms of dementia, and are responsible for the high prevalence of malnutrition among these patients, especially in the later stages. However, the change in eating habits in cognitive decline can have various presentations ranging from anorexia, or lack of appetite, to hyperphagia, and overeating including dysphagia and/or selective eating behaviors. The malnutrition that follows is indeed due to undernourishment or overnutrition, and this can be associated with a high level of distress for caregivers.

#### NEUROBIOLOGICAL REGULATORY MECHANISM OF FOOD INTAKE

Although the mechanism of appetite control and food intake is not yet fully understood, two pathways are believed to be involved: homeostatic and reward pathways. In the first, the hypothalamus regulates food intake by hunger and satiety through caloric and nutritional signals. In the reward pathway food the hypothalamus, several other limbic regions are involved (nucleus accumbens, amygdala, and hippocampus) and other cortical brain regions (orbitofrontal cortex, cingulate gyrus, and insula) are involved. In particular foods high in fat and sugar (e.g. chocolate) can have a rewarding effect provoking food intake despite satiety. On a neurotransmitters

level there are two regulatory mechanism of appetite: one stimulating which involves the secretion of ghrelin by an empty stomach and a negative regulatory mechanism which involves the secretion of leptin by adipocytes. Leptin is believed to activate oxytocin which decreases food intake.

#### EATING ABNORMALITIES IN A PARTICULAR FORM OF DEMENTIA: FRONTOTEMPORAL DEMENTIA (FTD)

In Frontotemporal Dementia (FTD) eating disorders constitute a core feature of the disease, especially the behavioral variant (bv-FTD), which is the most frequent FTD phenotype. In bv-FTD, eating abnormalities are seen in > 80% of patients, who present with overeating, binge eating and bulimia with significant progression in the 4 years subsequent to disease onset. Distinctive features of bv-FTD patients are gluttony, food cramming, continued eating, craving for certain foods (especially sweets), sometimes obsession for candies, and sometimes food stealing. Eating abnormalities in this variant can be overwhelming and very problematic for caregivers. In the other less frequent variants of FTD, which are the nonfluent/agrammatic primary progressive aphasia (nfvPPA) and the semantic variant (svPPA), eating abnormalities tend to be less frequent. In the semantic variant patients tend to be more selective in food choices and sometimes eat non-edible foods.

EATING DISORDERS IN DEMENTIA: BINGE EATING IN FRONTOTEMPORAL DEMENTIA (FTD), *continued on next page*

From a pathogenetic point of view, neuroimaging and postmortem studies support the hypothesis that an early feature of FTD-pathology, which is atrophy in the posterior area of hypothalamus, could also be responsible for eating disorders. In laboratory studies overeating can occur despite satiety and is associated with damage in the right-sided orbitofrontal-insular-striatal circuit. The hypothesis is that lesions in the striatum could impair the response to satiety.

Management of eating disorders in FTD constitutes a real challenge. First of all, patients require a thorough assessment of severity and frequency using the NPI scale for neuropsychiatric symptoms (in which 1 of the 12 categories assesses appetite and eating habits). Conventional approaches like caregiver counseling or assistance during meals are generally insufficient and FTD patients often require a pharmacological treatment. As therapeutic option selective serotonin reuptake inhibitors (SSRI) like fluoxetine, sertraline, paroxetine, fluvoxamine and citalopram have been used to treat disinhibition, sugar craving and excessive eating in bv-FTD with moderate improvement. From a physiological perspective an interesting report describes the use of Topiramate for overeating in FTD, the same drug used for binge eating and bulimia in non-demented patients with eating disorders. Topiramate is a sulfamate-substituted monosaccharide anticonvulsant that is associated with anorexia and weight loss; its use is reported in a patient with frontotemporal dementia (bv-FTD) with abnormal eating behavior who seemed to respond to treatment. While the exact mechanism of Topiramate in binge eating disorder and bulimia is not known, Topiramate acting as an

antagonist of glutamergic receptor alpha amino-3-hydroxy-5-methylisoxazole-4-propionic acid (AMPA) can reduce reward seeking behavior in animal models of substance dependence.

### CONCLUSIONS

Eating disorders are frequent neuropsychological symptoms of dementia which can be associated with varying degrees of malnutrition. In the behavioral variant of FTD eating disorders can be severe enough to require pharmacological treatment. Some authors have suggested that the type of eating disorder could address the differential diagnosis between frontotemporal dementia (FTD) and Alzheimer disease (AD), with anorexia and hyporexia more frequent in the latter, and overeating typical of FTD.

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### DATA-INFORMED DECISION MAKING IN LONG-TERM CARE FOR OLDER ADULTS: WHAT DO WE NEED?

Sil Aarts, PhD

Living Lab in Ageing and Long-Term Care, Department of Health Services Research

#### Key highlights

- Long-term care organizations (LTC), which provide care for some of the most vulnerable in society, lag heavily behind other care echelons in data-informed decision making.
- Living labs which include a network of diverse stakeholders, such as scientific researchers, care professionals, clients and their informal caregivers, can play a crucial role in data-informed decision making.
- A vision on data-informed decision making and a corresponding investment strategy are of utmost importance for data-informed decision making in LTC organizations.

Data is invaluable to health care: the availability of increasing amounts of data offers new possibilities to support personalized health care (1). Long-term care organizations (LTC) collect large amounts of data at client, staff and organizational levels. Data in Electronic Health Records (EHRs) (e.g., about the functioning and mental health status of a person) or data collected by technological devices such as sensors or wearables, and also qualitative data in the form of text from written documentation or conversations are collected (2). Hence, long-term care organisations collect a wealth of data and information. However, to date, the vast amounts of data are collected and stored, but not processed or analysed. Decisions in care are not made on the basis of data alone (data-driven), but also on previous experiences and qualitative input from clients, relatives and healthcare professionals (3). Currently, this data-informed decision making is lacking, suggesting that clients do not receive the most appropriate care.

LTC organizations see added value in data-informed care, but are overloaded with various types of data from different sources, such as EHRs and technological devices. Hence, LTC organizations are looking for ways to use this data to provide appropriate care and thus create value. This article discusses how data could become a more prominent part of long-term care for older adults, using an approach developed in our Living Lab in Ageing and Long-Term Care (4). The Living Lab

#### Example

Clients with dementia can display challenging behaviors (e.g., aggression), which results in diminished quality of life of these clients, and increased workload for nursing staff. Data obtained from a diverse set of sources can aid in our understanding of this behavior. Innovative analysing methods such as artificial intelligence (AI) and Natural Language Processing (i.e., an AI approach in which computers detect patterns in EHR text, for example) can be used for analysis to better understand the underpinnings of such behavior (2). Hence, data and innovative methods of analysis can provide time-scaled patterns (in months, days, hours or even minutes), by which behaviors or symptoms can be detected to facilitate timely intervention.

is a formal multidisciplinary network consisting of Maastricht University, nine large long-term care organizations, Gilde and VISTA College (vocational training institutes) and Zuyd University of Applied Sciences, all located in the southern part of the Netherlands (4).

#### (CREATING A) LEARNING NETWORK WITHIN LTC ORGANIZATIONS

Large bulks of data alone are insufficient to make decisions and predictions: the existence of data and innovative analyzing methods do not automatically lead to novel insights (3). A learning community is needed to discuss data-related issues.

DATA-INFORMED DECISION MAKING IN LONG-TERM CARE FOR OLDER ADULTS: WHAT DO WE NEED?, *continued on next page*



In 2020, we formulated the Core Group Data Science within the Living Lab: an existing network where knowledge is gained and shared about data, data science and data-informed care. The goal of the core group is to keep up with developments in other healthcare domains, such as hospital care, to expedite the use of data in LTC. This is done by sharing experiences and formulating practical daily care problems into research questions. All organizations contribute to this group (e.g., the content of meetings or grant applications), so that the tasks and output of the group are widely supported.

### VISION ON DATA AND RELATED DATA THEMES

Within long-term care organizations there are often dozens of different technological devices and systems that all collect data. Due to the diversity of technology and data, it is important to formulate a vision and central focus framework. By formulating the framework, we can ensure that data initiatives do not fragment, and that the use of data is of value for daily care. The purpose of a vision is to ensure that the use of data within an organization is aligned with the mission of an organisation: it should not describe separate entities. It should provide answers to questions such as: “Why do we find data important?”, “What data do we collect?”, and “What added value do we expect from data?”. In addition to documenting a vision, objectives that logically follow from this vision must be described (i.e., the strategy that an organization pursues with regard to data).

### INVEST IN DATA-INFORMED CARE

When formulating a vision on data, organizations should ask themselves whether and how they want to contribute to data-informed care: is this something that they want to invest in? The answer to this question may not always be a firm yes. If organizations want data to be a prominent part of daily work processes, a corresponding commitment and investment (including investment in time) are needed. For example, a 5-year strategy plan can aid organisations in stating their primary objectives, but also the way in which/ by whom these objectives will be achieved along with the (financial) resources required.

### MULTIDISCIPLINARY TEAMS

To achieve impact, a transition period is needed in which stakeholders from all organizational levels are empowered to learn with and from data (5); this may best be achieved by forming a multidisciplinary ‘data team’ within a LTC organization. A diverse group of people is needed for these teams (e.g., data/ICT specialist, innovation manager, care staff, scientist and client (representative)). Clients are especially important to ensure that the topics and results are understandable and relevant. The question arises as to which competencies are required for those involved: a multidisciplinary team must consider diversity in background, education (level) and experience of the members. Furthermore, “interaction” between the data team and the board/management of an organisation is warranted, for example, through periodic feedback (both on content and process).

### EMBEDDING IN DAILY CARE PROCESSES

To support data-informed decision-making in mental health care for older adults, data should be integrated into daily care processes. A theme such as this should be included in an organization's vision document: how does an organization want to use data to improve care for clients? How will care staff get on board with this new way of thinking? Suppose we want to translate the huge amounts of data collected into meaningful information. In that case, the findings must be checked and interpreted (initially by the data team) within the context of daily care processes.

### CONCLUSION

Using big data to generate new insights is a fairly new concept in LTC, and organizations may find it challenging to use data to optimize care processes. To set up a sustainable ecosystem for data-informed care, the topics presented in this guide can be discussed by and between stakeholders. Time, commitment and open communication are needed to ensure that data can lead to new developments aimed at improving daily care. Initiatives that support a close collaboration between science and daily care practices can

DATA-INFORMED DECISION MAKING IN LONG-TERM CARE FOR OLDER ADULTS: WHAT DO WE NEED?, *continued from page 15*

function as the perfect vehicle for achieving this goal.

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Dr. Sil Aarts is an assistant professor of the Living Lab in Ageing and Long-Term Care. The living lab is a formal multidisciplinary network consisting of Maastricht University, nine large long-term care organisations, Gilde Intermediate

Vocational Training Institute, VISTA College (secondary vocational education) and Zuyd University of Applied Sciences, all located in the southern part of the Netherlands. Her expertise lies in (ethical use of) data (science) and technology in long-term care for older adults. She founded the Core Group Data Science and is part of several committees regarding data and AI in healthcare, either within academia or outside.

### CAREGIVING, DEMENTIA AND INCONTINENCE

Joan Ostaszkiwicz, RN, GCert Cont Prom, GCertHE, MNurs-Res, PhD  
National Ageing Research Institute, Australia

#### Key highlights

- Up to one third of people with dementia experience incontinence at some point in the disease trajectory.
- Social taboos about incontinence can leave those with dementia and caregivers struggling to find helpful information and support.
- A new free online resource is available that addresses emotions and beliefs about incontinence, and provides information about maintaining continence and managing incontinence for those with dementia. building arm for lived-experience researchers) and four research programs will meet these aims.

People with dementia who experience incontinence deserve care that treats them with dignity and respect. Almost one third of people with a diagnosis of dementia experience difficulties with bladder or bowel function (1). These difficulties can have significant impacts on quality of life for both the individual and caregivers (2-5).

Despite the prevalence and impact of incontinence for people with dementia and caregivers, there is limited information available for support including strategies to delay or prevent incontinence, or information addressing the emotional and physical aspects managing incontinence (6).

To address gaps in current evidence and support, a research team from the [National Ageing Research Institute](#) (NARI) in collaboration with [Deakin FutureLearn](#) in Australia designed and disseminated a Massive Open Online Course (MOOC) on '[Caregiving, Dementia and Incontinence](#)'. The course, which is available to people from anywhere in the world, tackles the physical, psychological and psychosocial aspects of caregiving associated with dementia and incontinence.

Developed with the input of those living with dementia, caregivers and healthcare professionals, the course delivers free online training for both family and community caregivers which has received incredibly positive feedback.

With no prior experience or qualifications required, participants can gain knowledge, skills and resources to

assist with toileting, promote continence, and manage incontinence. The MOOC is a multimedia experience, with visual and audio learning tools, and includes a platform for social interaction with other caregivers.

The course provides helpful information about:

- Coping with the lived experience;
- Basics of bowel and bladder function;
- Promoting healthy bowel and bladder function and assisting with toileting and hygiene;
- Using continence aids and incontinence products, and protecting the skin;



CAREGIVING, DEMENTIA AND INCONTINENCE, *continued on next page*

CAREGIVING, DEMENTIA AND INCONTINENCE, *continued from page 17*

- Coping at home, out and about, and accessing information and support

In the 8 months since its release in August 2022, the MOOC has attracted more than 1,900 users across 69 countries – far exceeding initial expectations.

The MOOC provides people from around the globe with access to vital information and tools to support loved ones living with dementia and incontinence.

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I am a Registered Nurse and an academic. I lead a program of research at the National Ageing Research Institute that encompasses research on dementia care, continence care, loneliness and social isolation, carer support, and the

development and evaluation of knowledge resources to promote best practice. My aim is to build a global alliance to systematically tackle the neglected, stigmatized and complex biopsychosocial phenomenon of continence caregiving. The focus is on ethical, safe, person-centred continence care that upholds the rights and dignity of older people who require services and supports to maintain continence or manage incontinence. For further information or if you would like to contribute to my vision, please contact me at:

[j.ostaszkiewicz@nari.edu.au](mailto:j.ostaszkiewicz@nari.edu.au)

### EXPLORING AN INNOVATIVE PALLIATIVE CARE MODEL IN RURAL CHINA

Guangwei Ji, BSM<sup>1</sup> Peiyuan Zhang, MSW<sup>2</sup> Fei Sun, PhD<sup>3</sup>

[1] No.2 Staff Hospital of Wuhan Iron and Steel Company, Wuhan, China

[2] University of Maryland, Baltimore

[3] Michigan State University

#### Key highlights

- Palliative care started relatively late in mainland China. Despite extensive government promotion, it has encountered roadblocks in its dissemination due to the deeply rooted influence of traditional opinions toward life and death in the culture.
- In 2022, the total number of deaths in China was 10.42 million, among whom less than 0.3% had access to palliative care services.
- Future clinical and research efforts are warranted to develop strategies that combine high-quality palliative care services with universal accessibility

The concept of palliative care was first introduced to mainland China in 1988 and its development has been slow despite diligent promotion by the Chinese government. It was not until three decades later in 2017 that the Chinese National Health Commission launched a nationwide initiative to support pilot palliative care projects. So far, three cohorts of pilot programs have been implemented in 31 provinces of China, resulting in observable accomplishments and impact. However, its acceptance among the public remains limited due to the existence of death-avoidance within the culture, especially a deeply ingrained traditional view of an omen linked to death [1].

Great strides have been made worldwide in providing cancer patients with access to palliative care but its dissemination in rural areas has been limited [2]. Similarly, palliative care in China currently concentrates in large metropolitan cities with advanced socioeconomic development, mainly accessible to high-end client groups; it is often difficult for the general public to access such services. According to publicly available data, in 2022, the total number of deaths in China was nearly 10.42 million, but less than 0.3% had access to palliative care services prior to death. For this reason, it is of high urgency to explore innovative ways to effectively promote the concept of palliative care and improve the quality of end-of-life care for older adults in China. Below we describe a case with

a two-fold purpose: 1) to illustrate how the principle of palliative care is reflected in the process of assisting an older adult fulfilling their last wishes; and 2) to demonstrate the use of media coverage as a way of disseminating the concept of palliative care to the public.

On May 5, 2023, in Xiaogan City, Hubei Province, a family member of a 70-year-old patient with terminal stage cancer informed healthcare professionals that the patient was aware of his imminent passing, and his greatest wish was to go to Beijing, the capital of China, to see the national flag raising ceremony at Tiananmen Square. Upon learning about this situation, healthcare workers at a township health clinic in Xiaogan City decided to assist this older man in fulfilling this wish. However, the patient was experiencing a significant accumulation of fluid in both chest cavities, and with obvious respiratory distress undertaking a long-distance journey undoubtedly carried risks.

After a careful medical assessment, the patient received a chest drainage tube, which alleviated his respiratory difficulty. Accompanied by healthcare professionals and equipped with necessary medical equipment and medications, the patient embarked on a journey in an ambulance. After a two-day journey of over 1,100 kilometers, they finally arrived in Beijing, the capital of China.

EXPLORING AN INNOVATIVE PALLIATIVE CARE MODEL IN RURAL CHINA, *continued on next page*

EXPLORING AN INNOVATIVE PALLIATIVE CARE MODEL IN RURAL CHINA, *continued from page 19*

On the morning of May 9, the patient stood up and saluted the national flag during the flag-raising ceremony. With great excitement, he said, "I have finally fulfilled my last wish." This event touched the public, attracting the attention of numerous media outlets and raised public awareness about the quality of end-of-life care. Many people believe that this patient was relatively fortunate, because rural, older adults in China often lack the companionship of their children who have migrated to urban areas for employment. They can experience prolonged loneliness, suffer from age-related illnesses, and lack access to palliative care resources. As a result, rural older adults often are unable to have adequate quality of life during their final days.

As China has a large population, the resources for palliative and hospice care are insufficient to meet the needs of the general public. Based on our long-term practice, we believe that palliative care in China should be developed and made accessible in rural areas. We must actively assist grassroots health and social service institutions in cultivating competence in their healthcare and social care workforce to have palliative care available for rural citizens. We must address the substantial needs of different groups in China by combining high-quality palliative care services with universal accessibility.

However, due to variations in cultural beliefs and local customs, as well as economic reasons, the concept of palliative care is less accepted in rural regions compared to more urban settings which makes its promotion challenging. There is great demand for future medical practices and research to explore palliative care models which have been adapted to the cultural beliefs commonly held by rural, older adults.

The third Global Quality of Death Index evaluation showed that the quality-of-death ranking for Chinese individuals improved from 71st in 2015 to 53rd in 2021 [4]. While this

represents significant progress, a long journey remains in enhancing end-of-life care for all. Increasing access of palliative and hospice care in rural areas, and promoting inclusive palliative care, represents the direction where service professionals and advocates should focus their effort. This direction is essential to achieve the ultimate goal of improved quality of life for older adults with critical illnesses.

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Mr. Guangwei Ji is a professional in palliative and hospice care and is also an expert in breast and thyroid surgery. He is currently in charge of the promotion of palliative and hospice care. Additionally, he serves as an adjunct professor of surgery at Wuhan University of Science and Technology, a member of the Palliative Care Professional Committee of the Chinese Anti-Cancer Association, and a member of the Hospital Humanistic Construction Professional Committee of the China Life Care Association. His area of interest lies in caring for patients in the end stages of life with the aim of improving their quality of life.



### RESIDENTIAL'S MENTAL HEALTH TEAM IN PONTEVEDRA (GALICIA, SPAIN)

Javier Vicente-Alba, MD

Department of Psychiatry of Universidad de Santiago de Compostela, Spain

#### Key highlights

- Older adults living in residential care facilities are a vulnerable group requiring specific care.
- There is evidence on the benefit of cognitive stimulation both in groups and individually for older adults living with dementia.
- Social service and health care teams facilitate healthcare system access for older adults with dementia.
- In Pontevedra (Galicia, Spain), social service and healthcare teams have developed the use of cognitive stimulation as a group intervention for older adults residing in nursing facilities.

*Translated with [www.DeepL.com/Translator](http://www.DeepL.com/Translator) (free version)*

The care of institutionalised older adults has become increasingly relevant over time, especially after the COVID-19 pandemic, and following publications such as Wang (1) in the Lancet or ADI (2). Prior to the pandemic, it was known that institutionalised individuals are a vulnerable population with a higher rate of physical comorbidity, mental health problems (e.g., higher rate of depressive or anxiety disorders), and cognitive impairment, which leads to loss of functionality and greater dependence on others. Furthermore, the difficulties at a social level cannot be ignored which worsened during the pandemic, with included greater difficulty accessing healthcare, greater isolation and the risk of contracting COVID-19 itself.

Different proposals have been developed to improve access to healthcare for this at-risk population. Multiple studies have identified risk factors in institutionalised populations and seek to reduce risk through different pharmacological and non-pharmacological interventions (3). Reviews such as Gomez-Soria (4) or, more recently, the latest Cochrane review, indicate that there is evidence supporting both individual and group cognitive stimulation for improving cognitive function, socialization and quality of life for older adults with dementia (5).

In Galicia (Spain), social and healthcare programs have been developed, which recruit health professionals to work with those living with dementia promoting autonomy and quality of life.

In the Pontevedra O Salnés region, through the "Programa Galego de Saúde Mental Post-covid 2020-2024", there has been a socio-health care program for the last 2 years, which seeks to provide care to institutionalised patients, and complements the Psychogeriatrics Unit of the Psychiatry service.

It is a multidisciplinary team made up of a psychiatrist (Dr. Raquel Grande González) and a mental health nurse (Mrs. Verónica Ferro Bua).

Their approach is individualized to the patient and includes a detailed history and biography, review of symptoms, medication review, and functional assessment of independence. An individualized care plan is then established which can be modified overtime depending on need.

This type of intervention is the basis for standardised interventions such as WHELD, which present scientific evidence that improves quality of life, psychomotor agitation, neuropsychiatric symptoms and the use of psychotropic drugs in people with cognitive impairment (6).

Among the different activities carried out, the team would like to highlight the implementation of a group program for older adults with mild cognitive impairment admitted to a nursing home. Group therapy is one of the interventions that can be carried out with older people which promotes

RESIDENTIAL'S MENTAL HEALTH TEAM IN PONTEVEDRA (GALICIA, SPAIN), *continued from page 21*

sociability, and has been used for cognitive rehabilitation and the treatment of affective and anxious symptoms. Recent reviews, such as that of Rostamzadeh, A (7) emphasize the importance of psychotherapeutic and psychoeducational interventions in people with dementia.

Regarding the proposal of the Social and Health Team, it is a group therapy for people aged 60-75 years that aims to work on cognitive rehabilitation and executive functions (cognitive stimulation), while promoting individual autonomy and self-care.

The target population are those without cognitive impairment or with a diagnosis of Mild Cognitive Impairment. Many of residents of the facility where the program is carried out have a comorbid psychiatric pathology (severe mental disorder or personality disorders). Exclusion from the group is the presence of a diagnosis of dementia or a disorder or alterations of conduct or disruptive behaviour. The number of sessions is 8-10, with a duration of one hour and a fortnightly frequency. The different activities include exercises or cognitive stimulation tasks, the use of narrative techniques (poetry reading) and the use of music. Although the program is in its early stages, the team is hopeful to achieve positive results.

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Pontevedra's Social and Health care team: Dr. Raquel Grande (Psychiatrist) and Mrs. Verónica Ferro (Mental Health Nurse)