

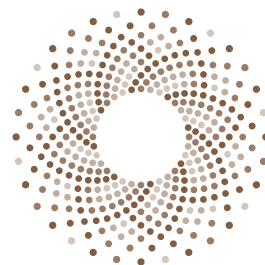
**World Dementia
Council** Leading the Global Action
Against Dementia

Global dialogue on psychosocial research in dementia: Transcript

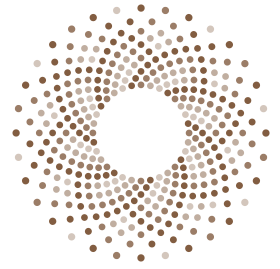
The dementia landscape project

26 October 2021





Co-chairs



Professor Anthea Innes

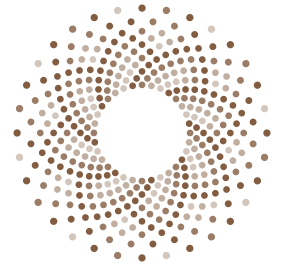
Anthea Innes is a social scientist who has specialised in dementia for around 25 years. She became the University of Salford's first Professor of Dementia in June 2016 and also took on the role of the Coles-Medlock Director of the Salford Institute for Dementia. The Institute brings together innovative research across the University to find ways of helping people live well with the condition. She worked at the University of Bradford as a Research Project Officer with the Bradford Dementia Group, where she also completed her PhD. She then worked as a Research Fellow and then a Senior Lecturer at the University of Stirling where she introduced the first worldwide postgraduate online programme in Dementia Studies. In 2011, she became a Professor at Bournemouth University where she launched and directed the Bournemouth University Dementia Institute (BUDI). Anthea is a renowned leader in rural dementia care research and has led numerous public engagement and dementia awareness projects.



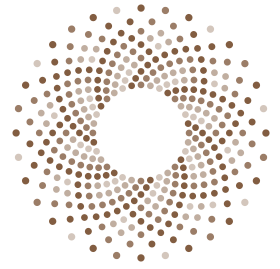
Professor Huali Wang

Dr Huali Wang is Professor and the Chair for Clinical Research, Director of the Dementia Care and Research Center, and Associate Director of Beijing Dementia Key Lab, Peking University Institute of Mental Health. She established the first dementia caregiver support group in China in 2000. Now she directs a training program for community doctors and service providers, and a train-the-trainer program for dementia caregivers support in China. She published five books on dementia care, including Smart Caregivers, China Memory Clinic Guideline and Practice Manual on Psychological Support for Older Adults. The care model has been partly adopted by WHO West Pacific Regional Office to develop the toolkit for community-based dementia care in low- and middle-income countries. Dr Wang is leading the National Platform on Clinical Dataset and Biobank of Major Mental Disorders. In regard to biomarker research of Alzheimer's Disease, she found that ApoE4 allele potentially modulates the hippocampal connectivity and the brain functional connectome.

Huali also serves leading position in national and international mental health research and service advocacy, including Secretary of International Psychogeriatric Association, Vice President of Chinese Society of Geriatric Psychiatry (founding member), Executive Vice President of Alzheimer's Disease Chinese (member of ADI), and WHO Global Dementia Observatory Focal Point for China. Dr Wang obtained Bachelor of Medicine from Beijing Medical University in 1994, and MD/PhD from Peking University in 2001. She has also attended Harvard Medical School (2002, 2012), the University of California, Irvine (2002-2005), and Duke University (2013).



Speakers



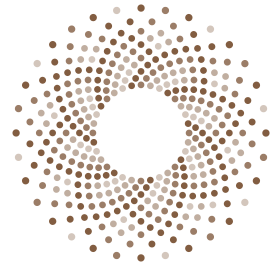
Professor Mary Mittelman

Mary S. Mittelman is research professor of Psychiatry and Rehabilitative Medicine at NYU School of Medicine and the director of the NYU Family Support Program, which was launched in 2016 with funding from New York State to provide comprehensive services to family caregivers of people with dementia. Trained in psychiatric epidemiology, she has been developing and evaluating psychosocial interventions for people with cognitive impairment and their family members for more than three decades. Dr. Mittelman was Principal Investigator of a randomized controlled trial of the NYU Caregiver Intervention (NYUCI), funded for 20 years by the National Institutes of Health. The study demonstrated that the NYUCI, a program that includes individual and family counseling, can improve the well-being of family caregivers and thereby help them to postpone nursing home placement of their relatives with dementia, with a major impact on social and medical care costs. Since then, Dr. Mittelman has participated in numerous replications of the original randomized controlled trial, and in community translations of the NYUCI.



Professor Perla Werner

Professor Perla Werner is a Full Professor at the University of Haifa in Israel. She has contributed to the expansion of knowledge in the area of psychosocial aspects of dementia and has pioneered the study of stigma in the area of Alzheimer's disease, its conceptualization, assessment and correlates. Prof. Werner has published over 300 papers and has received numerous grants from prestigious competitive sources such as the National Institute of Aging, the German-Israeli Foundation, the Israeli Science Foundation, and Alzheimer's Association. Prof. Werner is a Fellow of the Gerontological Society of America, serves as an Associate Editor in Stigma and Health and in the board of editors of other leading journals such as the International Journal of Psychiatric Gerontology, Journal of Alzheimer's Disease, and Clinical Interventions in Aging. She served as the Dean of the Faculty of Social Welfare and Health Sciences and as the Vice Rector of the University of Haifa.



Professor Bob Woods

Bob Woods is Emeritus Professor of Clinical Psychology of Older People, Dementia Services Development Centre Wales, Bangor University, UK. He has been a practitioner and researcher in the dementia care field in the UK for over 40 years. He trained and worked initially as a clinical psychologist in Newcastle-upon-Tyne, subsequently combining extensive clinical work with older people with academic appointments at the Institute of Psychiatry, London and University College London. From 1996 to his retirement in 2017, he was Professor of Clinical Psychology of Older People at Bangor University, Wales where he was Director of the Dementia Services Development Centre Wales. His research has involved the systematic development of evidence-based psychosocial interventions for people with dementia and their care-givers, including cognitive stimulation, reminiscence and life review and cognitive rehabilitation. His publications include practical manuals for family carers and care-workers as well as text-books and over 240 peer reviewed journal papers.



Hilary Doxford

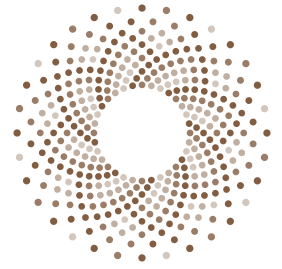
Hilary Doxford is a former Vice Chair European Working Group of People with Dementia, Ambassador Alzheimer's Society speaking nationally and internationally as a person with dementia. She was diagnosed with early onset Alzheimer's disease at the age of 53. Hilary Doxford also volunteers for the Alzheimer's Society in England as part of their research network and user involvement programme; is a champion for "Join Dementia Research;" and is a member of Dementia Alliance International. She is a founder member of the UK Three Nations Dementia Working Group, established in 2017 to advocate for people with dementia and to collaborate with professionals working in the field.



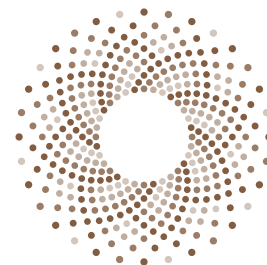


Lenny Shallcross

Lenny Shallcross is executive director at the World Dementia Council. Prior to that he was Head of Community Engagement leading programmes across the UK to establish Dementia Friendly Communities. This includes the Dementia Friends programme which is the biggest health social movement campaign delivered by 10,000 volunteers that have recruited 2 million individuals through a community, digital and corporate offer. Before working for Alzheimer's Society he worked in the UK government as a political adviser at the Department for Culture, Media and Sport and the Department of Health, as well as working in Parliament and for the Labour Party.



Global dialogue on psychosocial research in dementia



Tuesday 26 October 2021

06:00 PDT	San Francisco
08:00 CDT	Chicago
09:00 EDT	New York
14:00 BST	London
15:00 CEST	Central Europe
21:00 CST	Beijing



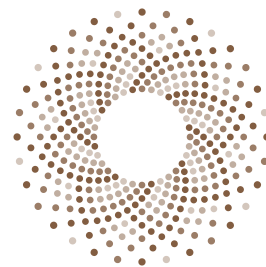
Discussion transcript



Lenny Shallcross
Executive director, World Dementia Council

Great. Well morning, afternoon everyone and welcome. I am Lenny Shallcross, the executive director of the World Dementia Council. Apologies for my, slightly incongruous background. I am in a hotel in Amsterdam, I'm here today for a meeting. So the bed you can see in the background is definitely not my own, I just can't work out how to turn on a background. So I realise many of you have participated in one of these global dialogues before or another council meeting. But for those of you who have not, the World Dementia Council was established following the London Dementia Summit, in 2013, hosted by the UK government as part of the G8 presidency. The council is chaired by Professor Philip Scheltens the director of the Alzheimer's center, here in Amsterdam. There are 24 individuals who are members of the council. Alongside them there are a number of government members. As you may have seen, we are holding an in-person summit meeting on December the sixth in London at the meeting, the council will publish a paper, looking at the progress the international community has made since the 2013 dementia summit. To help inform that, we have been organised in these global dialogues to hear from experts around the world on different aspects of dementia policy.

This is the 11th dialogue we've held previous conversations have been on biomarkers, clinical trials, technology dementia in lower-middle-income countries among others. Four hundred, global leaders have participated in the dialogues, and we've got two more coming up before concluding the series of them. One of which is on that Early career researchers, and one is a dialogue for people who are living with dementia.



We will produce a transcript of the meeting, which is the reason the meeting is being recorded. We don't release the recording. The people who contribute live, we will check the transcript with you. So feel free to say anything in this meeting, you will have a chance to subsequently edit it if you so wish. After all the dialogues we've continued the discussion by publishing collections of essays with reflections from people who took part in the meeting and a closing essay from a government or international figures who were have been active in the field. Early next month, we will be publishing the next collection of essays, which is on data sharing for research, with contributions, from some of those who participated in the dialogue earlier this year.

And the closing essay from Bill Gates, all our publications are published on our website. I would encourage you to share your thinking and this meeting either live or in the chat conversation. As you know, from the agenda we are kick-off with short opening perspectives, and then there's an open discussion. I'll just orientate you through the agenda. I'll hand over shortly to professor Wang, who will take through the opening speakers and then Professor Innes, will chair the virtual round table discussion at the end of which Hilary Doxford who I am sure many of you know will give closing reflections from the perspective of someone living with the condition. And after, after that, Professor Wang will give some closing comments and I will close the meeting. During the round table discussion I'm sure you are all well used to this, but if you can use the raise your hand function in zoom, it makes the flow of the conversation a lot easier. And with that bit of housekeeping done, and also with my, thanks to them, I'm going to hand over to the co-chairs and ask Professor Wang to start the meeting properly. Huali.

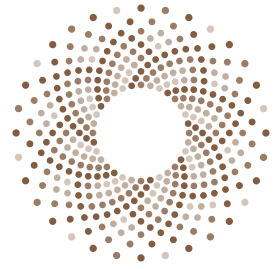


Professor Huali Wang

Professor and Chair for Clinical Research, Director of the Dementia Care and Research Center, Peking University Institute of Mental Health

Okay. Thank you very much, Lenny. I would like to add my welcome to everyone, and also thank my co-host professor Anthea Innes. I realise that many of you already know our speakers, but I would like to introduce. And I also thank the opening speakers. Professor Mary Mittelman, the professor of Psychiatry and Rehabilitation and Medicine at New York university in the United States. Professor Perla Werna, professor of community mental health at the university of Haifa in Israel and Professor Bob Woods, the professor emeritus of Clinical Psychology of older people at Bangor university in the UK. They will be sharing their thinking on different aspects of the field and afterwards I will turn the meeting over to Professor Innes who will chair the roundtable discussion.

Among the research priorities to reduce the global burden of dementia, the semantic topic research on the avenues of quality and delivery of care, emphasizes that high priority should be given to a psychosocial research into the models of care across the disease course. So now I would like to invite Professor Mary Mittelman to share her thinking on - NYU CI project and the evaluation of the project, and also the wider question of support for a person living with dementia, Professor Mittelman.



Professor Mary Mittelman

Professor of Psychiatry and Rehabilitative Medicine, NYU School of Medicine

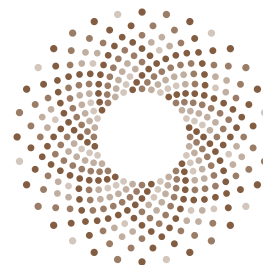
Thank you very much for inviting me to this conference. I now will have the pleasure or challenge of summarising 35 years of research in five minutes, but to start I think the trajectory of my research is relevant; I found some people doing what looked like an effective intervention back in the 1980s at NYU and I codified and developed what they were doing into what we call the NYU Caregiver Intervention and a study, a randomised control trial of that intervention was funded by the National Institutes of Health, ultimately for more than 20 years. And then additional funding was obtained from the National Institute on Aging to develop training materials and also to develop an online version, which was ahead of its time, given the pandemic was many years in the future. What we learned from the randomised control trial of 406 spousal partner caregivers who participated for as long as 18 years.

I would summarize by saying, "Counselling and support can have a dramatic and longterm impact on both the family caregiver and the person with dementia." The NYU Caregiver Intervention consists of six individual and family counselling sessions. First, an individual session followed by four family sessions and another individual session. Also, before the intervention occurs, there is a comprehensive assessment of the family caregiver finding out about her or his level of depression, anxiety, support system, who could be available to help him or her. And that assessment was repeated every four months for the first year and every six months thereafter, so that we could see both the short and the long term impact of the intervention.

The first, most significant thing that happened was, at the first follow-up just after the six counselling sessions, we saw a significant improvement in the caregiver's satisfaction with the social support from his or her family and friends. That led to significant and long lasting reduction in depression, reduction in stress reactions of the caregiver to the behaviour of the person with dementia. Also, we saw long-term improvements in physical health of the caregiver based on a self-reported health questionnaire. And those factors are all aspects of caregiver wellbeing and they led to a very significant reduction and postponement of nursing home placement.

So we published an article in Neurology in 2006 that showed the results of the first 12 years of follow-ups of the of the caregivers and people with dementia. In that time, we were able to postpone nursing home placement by about a year and a half compared to a usual care control group that got a lot of help. So the individual and family counselling, and in particular, the family counselling, I think, was the secret ingredient that made the cake rise. This study was replicated in the Three Country Study that was conducted in the U S the UK and Australia with (Henry Brodaty and Alistair Burns and me. And we demonstrated, in a shorter period of time, a significant improvement in caregiver, depression even though all of the people with dementia were taking donepezil.

So this intervention has an impact whether or not the person with dementia is receiving currently available drug treatments for dementia. And significantly for my own career, and to me, it wasn't the most important thing, but apparently in some ways it was, we



published a paper in Health Affairs in 2014 that showed that if the state of Minnesota, in which there are 5.5 million people, if every caregiver in the state of Minnesota received the NYU Caregiver Intervention, the state would save \$996 million. And it was because of that fact, not because of the caregiver wellbeing and the postponement of nursing home placement per se, but because of that cost savings, the state of New York funded 10 programmes across the state, I think it's unique, 10 family support programmes, based on the NYUCI model of counselling and support.

They, they allocated \$75 million for five years, and they've just reallocated funding for the next five years. And I was privileged to receive a grant for one of these, so I am running the NYU Family Support Programme and we've been able to help more than 2,600 caregivers since we were funded in 2016. So I think the cost savings was the ultimate driver of change in health policy, in New York State. I feel gratified that we've been able to help that many caregivers as a result of that finding.

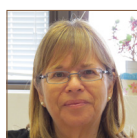
The intervention has also been replicated and translated in many places in the world, including with Perla Werner in Israel. And I think the underlying principle, that regardless of whether there are drugs or not, it is important to think about what comprehensive care for a person with dementia and their family member includes. And I think it must include, it must include psychosocial support in order to be successful.



Professor Huali Wang

Professor and Chair for Clinical Research, Director of the Dementia Care and Research Center, Peking University Institute of Mental Health

Thank you very much, Professor Mittelman. That's a great opening presentation to highlight the importance and also significance of caregiver intervention. Thank you very much. Now, I would like to turn to Professor Perla Werner to talk about the important issue of dementia stigma. She will reflect on what is dementia stigma, the myths that surround the topic and where we should go now from here. Professor Werner, please share your thoughts.



Professor Perla Werner

Professor of Gerontology, University of Haifa, Israel

Thank you very much. Thank you for inviting me. I would like to share with you my thoughts about the study of stigma in the area of dementia. First, let's try to define what is stigma. Stigma is defined as a set of cognitive attributions or beliefs, i.e., stereotypes as well as emotional reactions, i.e., prejudice and the behavioural reactions to stereotypes and prejudice. Stigma is associated to a person or to a group of persons with a discrediting mark.

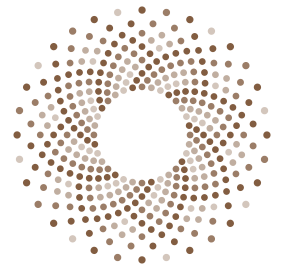
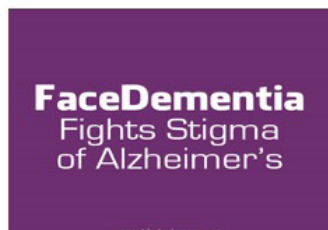
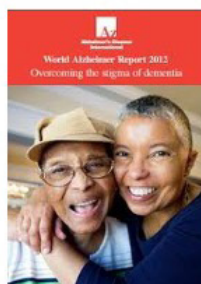
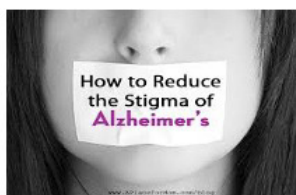
What is stigma?

Beliefs (stereotypes), emotions (prejudice), and behaviors (discrimination) associated to a person or a group of persons with a discrediting mark.

The topic of dementia stigma has attracted a lot of attention. There is a lot of anecdotal evidence that there is stigma towards people with dementia is very common. That's why many international organisations (such as ADI) have started initiatives to reduce dementia stigma.

Dementia Stigma

- It is widely assumed that dementia is associated with stigma
- International initiatives to reduce stigma




Chat function

The chat function was available throughout the dialogue for participants to ask questions of presenters and to hold discussion amongst each other. It began just under 20 minutes into the event and is displayed below. It does not necessarily correspond with the adjacent transcript in this document.

 **Paola Barbarino**

So nice to see so many familiar faces!!
Ciao everyone

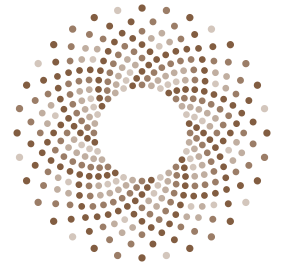
 **Professor Dawn Brooker**

Really good to see everyone!

 **Dr Heather Snyder**

So nice to
Good morning! Good afternoon! Good evening!

Empirical research in dementia stigma has increased also in the last years. In a systematic review I conducted published in 2014 and covering published studies from



1990 to 2012, we find 48 empirical studies. Forty of them were published during the 10 years from 2001 to 2012. I was curious to see what happened during the last year and I was astonished to find 33 new publications on dementia stigma from 2020 to 2021. The majority of the studies, included in the systematic review published in 2014 were qualitative. The majority of the studies published last year were quantitative. Across time the majority of the studies deal with public stigma. SLIDE But the question is ok we are publishing a lot about dementia stigma, but the interpretation of the data is based on myths or facts?

4

Research on dementia stigma

- Research in the area is increasing
- Systematic review (2014) covering January 1990 till April 2012
 - 48 empirical studies (40 published between 2001 – 2012)

Between 2020 – 2021

33 publications

The first myth relates to the question whether we know what are we talking about when referring to dementia stigma? Is it clear to everybody what dementia stigma is? I proclaim that while the word stigma is very clear in a conversational way, the very large majority of empirical studies on the topic, don't have a clear conceptualisation of the concept of dementia stigma. SLIDE And why is that? First very few studies present a clear, conceptual definition of the phenomenon. Second, studies relate mostly to dementia stigma as a non-dimensional concept. They don't differentiate between stereotypes, prejudice, and discrimination or behavioural reactions. Moreover, the concepts of stereotypes and prejudice are used interchangeably, and discrimination or other types of behavioural reactions are rarely examined. All these gaps lead to a reduction of a very complex concept. Third, the majority of the studies are a-theoretical. They lack an explicit statement of theoretical assumptions and limit, therefore, the possibility to evaluate critically the findings, make sound generalizations, and advance research. Fourth, in the research conducted till today, there is no differentiation between dementia and Alzheimer's disease. We know that Alzheimer's disease is the most common cause of dementia, but not the only type of dementia. Fifth, when studying dementia stigma, the majority of the researchers refer to the last stages of the disease. Lastly, but not less important is that there is no differentiation between the different types of stigma.



**Paola
Barbarino**

sorry I have to take my video off, I have an eye with some photophobia!



**Dr Claudia
Suemoto**

Good morning



**Professor
Vanina Dal
Bello-Haas**

Good morning everyone



**Dr Dianne
Gove**

Hi there. Sorry I have a camera plugged in and switched on but it is just not working. Nice to see everyone else :-)



**George
Vradenburg**

To Mary Mittleman: Is the NYU model covered by Medicare? Should it be?

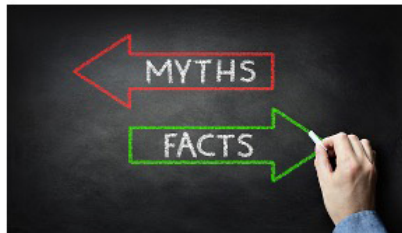


**Paola
Barbarino**

In the "different attribution" slide the dementia-anecdotal evidence, was collected on how big

The question is:

How much what we know about dementia stigma is based on



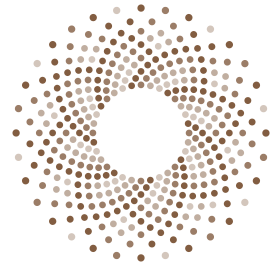
Myth 1

- The meaning of stigma in the area of dementia is clear and understood.

Facts?

- The concept of dementia stigma is blurred and not clearly defined

Public stigma refers to the stigmatic beliefs of the public or lay people. If these beliefs are internalised by a person with dementia, they convert to self-stigma. If they are internalised by a person that is close to a person with dementia – such as a formal or informal caregiver - they are referred as courtesy stigma or stigma by association. And if it's embedded by institutions and structures in the society, they are referred as structural stigma. I'm going to talk today only about public stigma.



a sample and in how many countries?
Thanks



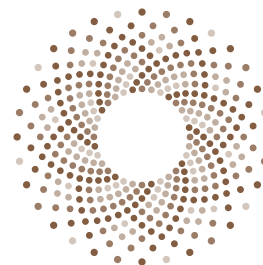
**Professor
Mary
Mittelman**

We tried to lobby for Medicare demonstration projects just pre-Trump, and had a lot of support in both houses of Congress, but the bill went into a coma when Trump was elected. I think the time may be ripe for renewed effort to explicitly cover caregiver support interventions. NY State could serve as a model, although the state is not currently measuring any outcomes.



**Dr Lee-Fay
Low**

Thank you Prof Werner for this great overview of stigma. I agree particularly with Myth 5, that we don't have good measures of stigma, and your points around social desirability and differentiation between measuring



Myth 2

- Public stigma towards people with dementia is very high

Facts?

- Levels of stigmatic attitudes towards people with dementia among the general public are low to moderate

Chang & Hu (2020), Gao, Sun et al., (2020), Lee, Hong, & Casado (2020), Polat, temel et al., (2021), Stites et al., (2018, 2021), Werner, Kalaitzaki et al. (2018), Werner, Raviv-Turgeman, & Corrigan (2020), Werner & Kim, (2021), Zhang & Cheng (2019)

The second myth states that dementia stigma is very high in the public. The facts show – as you can see in the references below – that the level of stigmatic attitudes among the public as reported by empirical studies is from low to moderate. SLIDE There are several explanations to these findings.

First of all, the stereotypes attributed to people with dementia are totally different from what we think in terms of anecdotal information. Research from different countries showed that the main stereotypes attributed to a person with dementia, are a lack of aesthetics, being filthy and having odour or being not well dressed, and being unpredictable. The main emotional reaction, is fear, but not fear to what the person with the disease will do to him/herself or others, but fear of getting the disease. Another common emotion reported in studies is a feeling of uneasiness, of discomfort in the presence of a person with dementia. But, overall, the feelings that are aroused in a relation to a person with dementia, are positive such as sympathy, and pity (although I'm leaving pity with a question mark, because that's something that I want to discuss with you further on). Regarding the public behavioural responses, mostly are positive as well, and they include a willingness to help the person with dementia. The few negative reactions reported – such as segregation or treatment coercion, were found when describing people in the last stages of the disease.

But the relatively low levels of public dementia stigma found in studies might be related to measurement issues rather than to the presence of stigma. The vast majority of the studies conducted till today have examined stigma by using the measure of explicit attitudes. Explicit measures, i.e., based on the self-report of the participants, face multiple biases, such as social desirability – meaning that the person reports what he thinks that researchers want him to report. To the best of my knowledge there are only a few empirical studies using implicit measures, showing that stigma is much higher using this type of measures.

types of stigma. I'm not sure I agree with your interpretation of data around Myth 4, and suspect that we might need more data around the relationship between ageism and dementia stigma. We certainly need more thinking and research around how we can decrease stigma (education certainly is not sufficient)



**Professor
Brian Lawlor**

What are your thoughts on hope and pathways to action to combat stigma? Also, is the concept of brain health and taking a brain health approach changing the face of dementia stigma?



**Professor
Allison
Lindauer**

Thank you for the overview of stigma! An important topic. Stigma seems to vary by subculture.

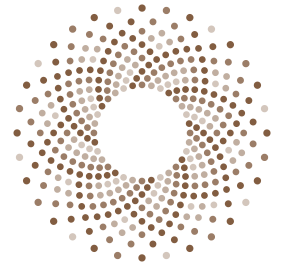
Myth 3

- Pity is a positive emotional reaction.

Facts?

	Compassion	Pity
Willingness to help	.77***	.21**
Coercion	.02	.41**
Segregation	-.41***	.16**
Avoidance	-.22**	.23**

Myth 3 – Pity. In the area of mental illness stigma, pity is conceptualised as a positive feeling. My own research, as well as discussions with many experts in the area, shows that although higher levels of pity are associated with increased levels of willingness to help as compassion does, it does not reduce negative behaviour and reactions as compassion does. This means that pity is actually not such a good feeling to have. SLIDE To clarify these findings we have to try to understand the psychological and philosophical meaning of pity. When feeling pity the person feels like a spectator, like looking from outside instead of really trying to be part of the problem. Pity even reflects some kind of superiority-inferiority relationship. So it's not such a good feeling. And it's the most common and highest emotional reaction reported towards people with dementia.



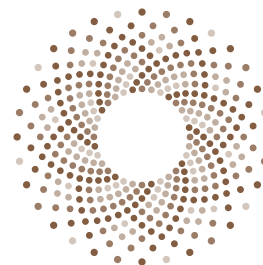
**Paola
Barbarino**

Prof Werner in your presentation on stigma, unless I missed it, I did not see a reference to ADI's World Alzheimers report 2019 on attitudes to dementia globally which was co-authored by the LSE. Is there any reason for that?



**Professor
Mary
Mittelman**

We should also consider psychosocial interventions for people with dementia together with their family caregivers. For example, our chorus, The Unforgettables, had demonstrable effects on both caregiver and person with dementia and the concerts they gave, prepandemic, undoubtedly reduced all aspects of stigma -- self stigma, stigma by association and public stigma.



Myth 4

- Dementia stigma is associated to negative attitudes towards older people (ageism)

Facts?

- Stigma is higher towards a younger person rather than towards an older person with dementia (early/late onset dementia)

Lockeridge & Simpson (2012), Werner, Turgeman, & Corrigan (2020)

The fourth myth is that dementia stigma is associated with ageism towards older people. Of course, the majority of people with dementia are older people - so are we indeed witnessing double stigma – i.e., stigma based on dementia and on age? Actually the very few studies that studied also stigma towards younger people, comparing early onset to late onset dementia, found that the levels of stigma are higher towards the younger people. Why is that? First of all, you have to remember that stigma is attributed to a person or a group of persons that are different and have been marked therefore as abnormal and different. In the case of dementia these are the younger people with the disease. Second, as previously stated, the main attributions in mental illness stigma is the person being perceived as violent or as dangerous. Younger people are stronger and they therefore be perceived as more dangerous and more violent than older people. Third, and concentrating on the older rather than on the younger person with dementia, older people are frequently the target of paternalistic or benevolent ageism. They are being perceived as warm people, nice people much more than younger people.



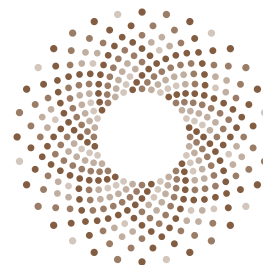
**Professor
Kristen
Jacklin**

Thank you Dr. Woods. This is a very helpful presentation. I think refreshing our look at outcomes is necessary and should include a health equity lens. Different cultures will have different values that impact what outcomes are important to them and we need to recognize that outcome expectations will vary considerably by socio-economic status. There are also large disparities in access to psychosocial interventions. How do we design interventions that can be delivered and sustained outside of the university/teaching facilities.



**Dr Gloria
Wong**

Thank you Bob. Your point that QoL measure is a game-changer appeals to me. I'm wondering what your and



Myth 5

- Clear and validated measures of dementia stigma are available

Facts?

- Measurement is a major issue in the study of dementia stigma
- A number of measures are used but:
 - Many don't describe psychometric characteristics
 - Were adapted from scales developed for other types of stigma – FS-AD-S
 - Don't assess all dimensions

The fifth myth is that we have available good valid measures for assessing public dementia stigma. Indeed, this is not the case. There are several published measures to assess public stigma regarding dementia, but very few are validated. Moreover, the majority are not multi-dimensional, meaning they don't assess all the dimensions that we were talking about - the cognitive, the affective and the behavioural dimension – but rather a global measure of dementia stigma. Furthermore, many of the scales are adapted from measures that were developed for other types of stigma like the scale that we developed and validated to assess dementia family stigma.

others' thoughts are about whether we need another game-changer now, to move research on psychosocial intervention forward - one that aligns with the philosophy that underlies those psychosocial interventions/ care. Could it be person-centredness (which is not only about individual QoL), or quality of interpersonal relationship (or family relationship in some cultures)?



Professor Alison Phinney

I agree Kristen - engaging the community/ general public in creating & delivering new ways of engaging people with dementia in meaningful activity is critical. This means expanding beyond universities and health care environments.

Myth 6

- The media perpetuates dementia stigma

Facts

13 June 2014 Last updated at 11:40 (GMT)

Dementia is 'one of greatest enemies of humanity' - PM



A "big, bold global push" is needed to beat dementia, David Cameron has told a summit in London. Related Stories

MIDDLE-AGED SPREAD IS 'DEMENTIA TIMEBOMB'

EXPANDING middle age waistlines could lead to a 40 per cent rise in the number of people with dementia within a few decades, say scientists. Experts at the UK Health Forum calculate that if Britain's obesity problem continues to grow, 7 per cent of over-65s will have dementia by 2050. This contrasts with 5 per cent today and equates to at least 200,000 extra cases. It highlights how obesity harms memory but high blood pressure and cholesterol can both affect the blood supply to the brain. Around a quarter of adults in England are obese and this is expected to rise to 40 per cent for men and 30 per cent for women by 2050, the European Congress on Obesity heard.



Care home 'jail' for dementia patients

Report exposes shameful treatment of vulnerable GPs

A report by the Royal Society of Medicine has exposed the "shameful" treatment of vulnerable GPs in care homes. The report, titled 'Dementia: A Care Home Jail', says that many GPs in care homes are treated like prisoners, with no freedom of movement and no access to the outside world. It calls for a complete overhaul of the system to ensure that GPs are treated with dignity and respect.

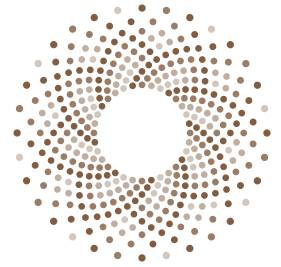


Nightly News | Jun 26, 2014

Scientists test Alzheimer's vaccine

March 11: The results of current clinical trials could mark a major turning point in the fight against Alzheimer's. NBC's Robert Bazell reports in Part Two of "Living Longer."





The sixth myth is that the media perpetuates dementia stigma. What do the facts say? This is not a myth, unfortunately. The media continues to use stigmatic language and metaphors to describe a person with dementia, and the pictures showed are from people in the last stages of the disease.

19

Myth 7

The framework of education, contact, and protest interventions (used with other conditions) will help reduce dementia stigma

Facts?

The interventions are conceptually and methodologically poor
The efficacy of the interventions is small – at the best

Bacsu, Johnson et al (2021), Kim et al. (2020); Werner et al. (2017), Werner, Van Gorp et al. (2021)

The seventh myth refers to the development of interventions to reduce dementia stigma. The common sense and belief is that the main interventions used to reduce the stigma in mental illness will be effective also for dementia stigma. The very few studies evaluating interventions to reduce public dementia stigma showed that their effectiveness is very small, and limited to a short time after participating in the intervention. In the last years we are witnessing more efforts with the worldwide initiative of dementia friends.



**Paola
Barbarino**

I think this great presentation on interventions, as the one of Mary, hits the nail on the head. There is so much great research right there but so little take up from national healthcare systems. Incentives, as Mary points out are key. If governments see savings we have a chance but the context and cultures for each implementation are so different and varying. Does anyone else have positive examples of implementation like Mary? write to me directly perhaps over email p.barbarino@alzint.org



**Professor
Bob Woods**

Hi Mary - great to see you again. I agree that joint interventions are well worth pursuing further. Our joint reminiscence groups didn't demonstrably benefit family caregivers, unfortunately.

Summary

Myths	Facts
Clear conceptualization	Blurred conceptualization
High levels of stigma	Moderate levels of stigma
Stereotypes of dangerousness	Stereotypes of lack of aesthetics
High negative reactions	High positive reactions High feelings of pity
Higher levels towards older people	Higher levels towards younger people
Clear and valid instruments	Non-specific and un-validated instruments
Media reinforces dementia stigma	Changes are developing slowly
Stigma reduction interventions are successful	Small to no change in dementia stigma

Where do we go from here?

So we see that we have many myths and we have many facts. Where do we go from here? I believe that dementia stigma is present, but the question is, what is this stigma? How is it conceptualized? This is important because only after a clear definition of the phenomenon we can turn to reduce it.

This is extremely important because the definition of dementia is also changing. We are moving away from a pathological biomedical model to a more or psycho-social-cultural model seeing dementia as an holistic concept, embedded in society, in culture, and stressing self-determination, autonomy and enablement.

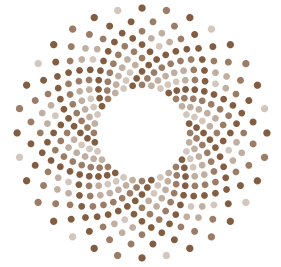
Also the recent bio-molecular developments in the diagnosis of the disease at a preclinical stage, and the progress in the understanding of modifiable risk reduction factors, change the perception of a person with dementia. Now we have a more proactive approach. The person with dementia does not lose his/her autonomy, and decision-making capability immediately with the diagnosis. Moreover, similar to other disease, people have responsibility at younger ages to embark in health behaviours to reduce the risk of developing dementia. Will these changes increase? decrease? stigma. We have much work still ahead of us. Thank you very much.



Professor Huali Wang

Professor and Chair for Clinical Research, Director of the Dementia Care and Research Center, Peking University Institute of Mental Health

Thank you very much, Professor Werner. That's a wonderful talk and also a comprehensive review of the research literature regarding stigma. And also thank you very much for uncovering the myths and providing the facts about dementia. Yes, we can have more discussion later. Now. I would like to invite our final opening speaker,



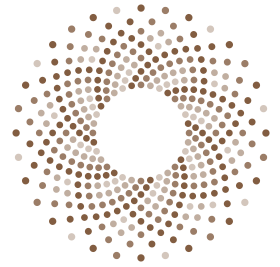
Dr Lucia Crivelli

In argentina we designed a program to link highschool students and MCI and mild dementia patients during the pandemic. Students assisted remotely the elderly in teaching them how to use technology. WE measured ageism in students and significant changes were reported. This program was a nice way to narrow the gap between generations. This gap that the pandemic has broadened enormously.



Dr Lee-Fay Low

One issue around adapting and scaling is that sometimes sufficient details of the psychosocial intervention aren't published. It would be really helpful to have more published details around the 'black box' of some interventions.



Professor Woods. He's going to share his thoughts about psychosocial support for people who are living with dementia. Professor Woods please.



Professor Bob Woods

Emeritus Professor of Clinical Psychology of Older People, Dementia Services Development Centre Wales, Bangor University

Psychosocial interventions for people living with dementia

Bob Woods
Emeritus Professor
Bangor University, Wales, UK
26 October 2021

Thank you for this opportunity to share a few thoughts on an important aspect of psycho-social research in dementia: psychosocial interventions directly with people living with dementia.

Psychosocial interventions for people living with dementia - 1

- A growing evidence-base on efficacy and effectiveness
 - E.g. Cochrane reviews; McDermott et al., 2019; Knapp et al. 2021;
- What are we aiming for?
 - 'Magic moments'A happy hour.....feeling good for weeks.....life changing
 - Better score on the MMSE.....improved cognition.....better performance on real-life tasks
 - Improvements in 'neuropsychiatric symptoms'
 - Quality of life measures have been game-changing – do we now need a refresh in terms of indices of change? (e.g. Clarke et al., 2020)
- Meaningful activities v. 'therapeutic interventions'
 - Arts and music based; intergenerational; CBT for depressed mood; cognitive rehabilitation

This area has been the subject of research for over 60 years now, going back to the 1950s; I've had the good fortune to be contributing to this field for almost three quarters of that time. Over the years we have seen a growing evidence base on efficacy and effectiveness.



Dr Dianne Gove

I like Mary's point about it all being about support and think that consequently, it is really important to make a big effort to try to ensure that people from marginalized groups are involved in the psychosocial research, which informs the development of the support that is eventually available.



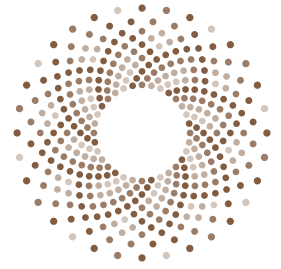
Professor Vanina Dal Bello-Haas

Agree with Esme Moniz-Cook ... we seem to have been focusing on 'lost capabilities' versus 'remaining capacities'. ... how to capture?



Dr Aimee Spector

Joel Sadavoy raised the very important point about training. At UCL, together with PKU and HKU; we are currently developing a



I'm not going to go into great detail on this; it is documented in several Cochrane reviews and there's a very nice review of reviews by McDermott et al. (2019). In relation to cost effectiveness there's evidence also; very recently, Martin Knapp and colleagues have published an interesting health economics analysis around one particular intervention, cognitive stimulation therapy (Knapp et al., 2021). So, although there have been many disappointments along the way, and the interventions perhaps are not as dramatically effective as we would like, there is a growing accumulation of evidence that psychosocial interventions can be helpful for people living with dementia. This is despite this area having been arguably the poor relation of research on interventions for people with dementia.

But what I want to do in this brief contribution is to raise a few more issues for the field going forwards. These arise from looking back, reflecting on some of the issues that have emerged, and some of the mistakes that have been made, by myself as much as anyone.

My first question is: what is it that we are actually aiming for? There often seems to be confusion around that. At its most elemental, perhaps we're just aiming for 'magic moments'. What do I mean by that? Anyone who has worked directly with people with advanced dementia will recognise those times of connection and engagement, where you feel that the person with dementia connects with you, perhaps has a big smile on their face or makes a positive action. It may just be fleeting, but there is something there, something has happened, and, for a moment, you feel you have made a difference. Or it may be that we are offering an activity, a group or an individual intervention that gives a 'happy hour'. Does it have to extend beyond that? Or is it enough that for that brief period of time the person had good feelings? So often it seems to be the case that we are hoping that our intervention will keep the person feeling differently for weeks afterwards, or perhaps we even hope that it will be life-changing: that six months, nine months, a year, 18 months later, the intervention will still be making a difference. Is this realistic? Is this necessary?

There can be confusion about what we are really aiming for and which of those aims might be considered worthwhile. Looking at the literature, one could be forgiven for thinking that our main objective is to gain a few points or perhaps even a point and a half on the Mini Mental State Exam, (although other cognitive measures are available!) or to improve neuropsychological functioning, or even perhaps to improve performance on everyday tasks through the person setting goals and seeking to achieve them. Or perhaps we are trying to improve neuropsychiatric symptoms (or whatever the preferred terminology might be), for those difficulties and distress that some people with dementia will experience.

One of the biggest game-changers over the years has been the development of quality of life measures, with Rebecca Logsdon and Linda Teri's QoL-AD leading the way. This development meant that we could begin to look at outcome measures well beyond just the location of the person with dementia (at home in the community or in a nursing home), important though that is. We could now think about how life might be experienced by the person living with dementia.

However, increasingly as we look at intervention studies incorporating quality of life outcome measures, it appears that they do not always quite tap into the areas that might

website aiming to direct people towards trainings of evidence-based interventions for dementia. We have been struck by how few interventions have accessible training courses, making implementation much harder.



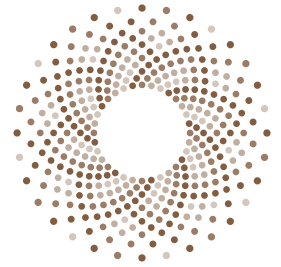
**Professor
Bob Woods**

Hi Lee-Fay, Yes - before the RCT there should come a treatment manual - an evidence base can't be based on one study and we can't integrate results from different studies without an in-depth perspective on what was done. This doesn't mean it can't be individualised.



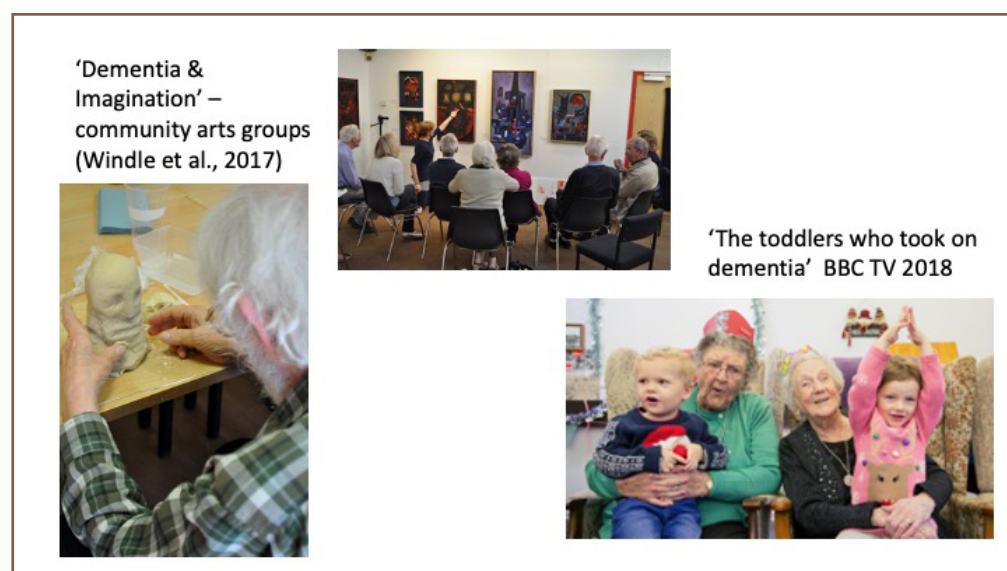
**Professor
Joel Sadavoy**

A broader problem of stigma is the general stigma against mental disorders.



be changing for the people involved. Perhaps we now need to have a refresh in terms of indices of change and begin to think about outcomes that can be more individualised, that reflect the individual person's desires and goals – the things that really matter to them and their individual quality of life (Clarke et al., 2020).

The next area I want to consider is what might be described as a 'proliferation of therapies'. Often people talk loosely about art therapy, music therapy, pet therapy, but what we're really talking about in many instances is the therapeutic use of arts, the therapeutic use of music, animals or whatever. There's a great many meaningful activities that can become reified as 'therapies'. We need to think very carefully about what it is that we are talking about in our interventions. Cognitive behaviour therapy for depressed mood or cognitive rehabilitation certainly require therapeutic skills. On the other hand, meaningful activities may well be very valuable, but that doesn't mean that they actually have a therapeutic process; we need to understand what underlies them and any effects they may have.



Whether its community arts projects (Windle et al., 2017), visits to galleries and museums, making music, singing in choirs or intergenerational work, seeing people with dementia engage and energised by contact with children and young people, are these simply excellent and laudable examples of social inclusion or is there a more elaborate theory of change we should explore?

We should certainly be aware that one size does not fit all, there will be individual preferences. Apparently, not everybody likes small children, and certainly not everybody likes dogs or other pets. People have different ideas. In one of our reminiscence group studies we recruited a large number of people with dementia and their carers, half were randomised to attend the reminiscence groups. A quarter of the people randomized to attend the groups attended no more than three of the 12 sessions that they were offered. It seemed that for some it was logistics, but for many, they just did not like groups. There will be different things that are appropriate for and relevant to different people. Some people are uncomfortable in groups, some people prefer different sorts of activities. Some people do not want to focus on the cognitive changes. In our work on cognitive rehabilitation, we find that a proportion of people find it hard to set goals. They say, well,



Dr Deborah O'Connor

Agree with Esme that we have been constrained by the psychosocial model that focuses heavily upon change at the individual (inc. familial) level. Finding interventions that bridge personal and structural (socio-cultural) are also required. Also require a more intersectional approaches.



Professor Mary Mittelman

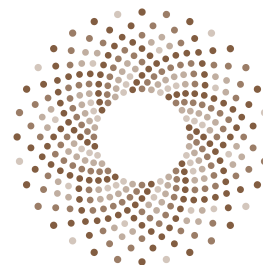
We developed online training and wrote a book about how to do the NYUCI. Nevertheless, I think cultural differences make collaborating with partners from the culture we are trying to reach is imperative



Professor Allison Lindauer




The National Alliance for Caregiving and AARP's report shows that 30% of those

no, actually I'm happy as I am, I don't feel the need to identify areas of change, I'm just happy as I am.



Psychosocial interventions for people living with dementia - 2

- One size does not fit all
 - Individual preferences
 - Individual differences: what works for whom?
- Randomised Controlled Trials (RCTs) are not always the answer
 - Can be premature – feasibility first;
 - pragmatic RCTs reflect real world better
 - Multi-component interventions or comparisons of interventions?
- Is it just implementation research that we need?
 - Context is crucial to implementation – ecopsychosocial interventions (Zeisel et al., 2016)
 - Geopolitical (e.g. Stoner et al., 2021)
 - Cultural (e.g. Aguirre et al., 2014)
 - Temporal
 - More options still needed to enable all people with dementia at every stage of their dementia journey to live well



We need to understand much more about individual differences, what works for whom. It is reasonably clear that many of our interventions are more suitable for people with mild or moderate dementia rather than advanced dementia and vice versa. But we need to get much better at understanding what sorts of interventions are going to be helpful for what sorts of people living with dementia. We need to understand more about aspects like anxiety and depression in dementia and target interventions for those difficulties that people experience rather than providing interventions in a general un-targeted sort of way.

We've seen exponential growth in the number of randomised control trials in the field and it has been really good to see the quality of the available research becoming better and better. But sometimes I do worry that there is a rush to carry out a randomised controlled trial almost before the intervention itself has been properly defined and understood or properly tested for feasibility and developed to a stage where we know what it is that we are doing. In our research, we have tended to use pragmatic randomised control trials, which reflect the real world better, where you don't try to disaggregate each little component of the intervention. Rather you understand that the meeting of the group, the social aspects, the incidental interactions, they are all part of the intervention. In this way, I guess most of our interventions should be described as multi-component interventions. There is a therapeutic package; even if we consider we are doing 'pure' cognitive training, for example, there are almost certainly other aspects around the delivery of the intervention that add to that package.

One of the things we need to consider is how we define what are the components that make the intervention work? What are the 'magic' ingredients? I can envisage that increasingly one intervention will be set against another in comparative studies, but is that approach really going to be helpful? Suppose that we found that, for example, reminiscence was better than cognitive training, is it not likely that in fact it will be better for some people, but not for others? Again, we need to understand what works for whom and that is actually the key issue, rather than the average effects on large groups of people with dementia.

who live with their care-recipient report feeling lonely.



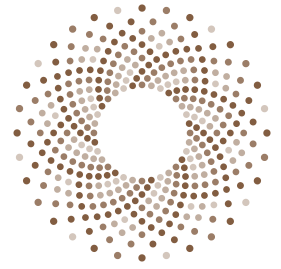
**Professor
Kristen
Jacklin**

Kate Smith UWA, did some great work on revisioning quality of life with Aboriginal Australians "Good Spirit, Good Life...": <https://pubmed.ncbi.nlm.nih.gov/32191314/>



**George
Vradenburg**

Should we be focusing so specifically on particular interventions and outcome measurements. Or should we focus on enabling and incentive structures? For example, the arts in many societies are supported through tax incentives and philanthropy ... and the arts have 'scaled' , proliferated and are 'person centered' because families choose their favored art form ... should we really try to design specific



The final issue I wanted to highlight is the issue of implementation. It is really great to hear Dr Mary Mittelman talk about how her programme for family caregivers has been implemented widely around the world. We need to understand how psychosocial interventions, for which context is so important, can best be implemented outside the setting of the original development and evaluation. ‘Ecopsychosocial interventions’ is a term that has been coined (Zeisel et al., 2016), reflecting the importance of the environmental culture for these interventions. For some interventions directly with people with dementia implementation in other countries or in other health systems has not been so successful as in the original context. There have been problems taking an intervention that works well in one country to another. There have been really good developments recently around cognitive stimulation, taking something that was developed very much in a British context, to Africa, to India, to South America, and to other countries in Asia. In order to achieve that, there is a lot of adaptation that is required for different cultures, different political systems, different healthcare systems, different cultures of family care, different values (Aguirre et al., 2014). And those all need to be understood as we adapt and trial out different interventions (Stoner et al., 2021).

interventions or rather, like Mary, enabling families to better make their own choices?



Professor Dawn Brooker

The concept of social health is very important



Professor Rose-Marie Drees

I think that besides social support helping people with dementia and caregivers adapt to the consequences of dementia and refine an emotional balance is at least as important



Professor Huali Wang

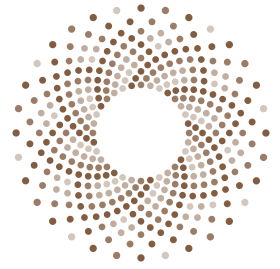
We published the manual of caregiver support (8 modules). The users are encouraged to adapt in local cultural background as cultures and customs vary across the country.

References

- Aguirre, E., Spector, A., & Orrell, M. (2014). Guidelines for adapting cognitive stimulation therapy to other cultures. *Clinical interventions in aging*, 9, 1003.
- Clarke, C., Woods, B., Moniz-Cook, E., Mountain, G., Øksnebjerg, L., Chattat, R., Diaz, A., Gove, D., Vernooij-Dassen, M., Wolverson, E. (2020). Measuring the well-being of people with dementia: a conceptual scoping review. *Health & Quality of Life Outcomes*
- Knapp, M., Bauer, A., Wittenberg, R., Comas-Herrera, A., Cyhlarova, E., Hu, B., ... & MODEM project team. (2021). What are the current and projected future cost and health-related quality of life implications of scaling up cognitive stimulation therapy?. *International Journal of Geriatric Psychiatry*.
- McDermott, O., Charlesworth, G., Hogervorst, E., Stoner, C., Moniz-Cook, E., Spector, A., ... & Orrell, M. (2019). Psychosocial interventions for people with dementia: a synthesis of systematic reviews. *Aging & Mental Health*, 23(4), 393-403.
- Stoner, C. R., Lakshminarayanan, M., Durgante, H., & Spector, A. (2021). Psychosocial interventions for dementia in low- and middle-income countries (LMICs): a systematic review of effectiveness and implementation readiness. *Aging & Mental Health*, 25(3), 408-419.
- Windle, G., Joling, K., Howson-Griffiths, T., Woods, B., Jones, C., Van de Ven, P., ... & Parkinson, C. (2017). The impact of a visual arts program on quality of life, communication, and well-being of people living with dementia: A mixed-methods longitudinal investigation. *International Psychogeriatrics*, 1-15.
- Zeisel, J., Reisberg, B., Whitehouse, P., Woods, R., & Verheul, A. (2016). Ecopsychosocial Interventions in Cognitive Decline and Dementia: A New Terminology and a New Paradigm *Am J Alzheimers Disease & Other Dementias*. 31: 502-507.



There is also the temporal change in culture with changing times. What was acceptable 30 or 40 years ago would no longer be acceptable in terms of our hospital care, our care homes, our care in the community. There have been huge changes in expectations, major changes in what people living with dementia and caregivers now expect from those providing care, and we need to reflect that in the interventions that we develop. The question is sometimes asked as to whether we should just focus on implementing what we already know, rather than developing new interventions and doing yet more research on their effectiveness. I tend to agree that there is a lot more that could be done in terms of implementing what we know already, but I do not think that this is nearly enough. We need more well-researched therapeutic options if we are really going to help people living with dementia at every stage of their journey to live well and to have the life that they deserve.



Professor Huali Wang

Professor and Chair for Clinical Research, Director of the Dementia Care and Research Center, Peking University Institute of Mental Health

Thank you, Professor Woods. That's a nice presentation regarding the psychosocial intervention for presence with dementia. And also I would like to thank our three openings speakers Professor Mary Mittelman, Professor Perla Werner, and also Professor Bob Woods talking about different aspects of psychosocial intervention, psychosocial research on dementia, caregiver intervention for people living with dementia, and the stigma, how we can overcome stigma in a society. As we are running a little bit over time, now I'd like to turn to Professor Innes my co-chair.

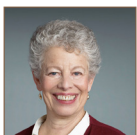


Professor Anthea Innes

Professor of Health Aging and Society, McMaster University

Thank you very much, Professor Wang. I'd also like to add my thanks to the opening speakers, for sharing their perspectives. And there are so many interesting aspects to psychosocial research. And I think those three presentations really gave us a good overview. We had a focus there on caregivers, persons with dementia and also stigma, which impacts on multiple levels. So I think we now have a really good opportunity for a dialogue for about half an hour to, to focus on a whole range of questions that are already appearing in the chat, and I guess some of them already are focused in on what works. When does it work? In what context does it work? How do we know we've actually got a successful outcome? And how do we upscale things so that we, we get bigger change for more and more people.

So, as Lenny said at the beginning, this dialogue is an opportunity for all this international group of expert leaders in the field to share their thinking on where we are and where we need to get to. So it's a round table conversation. You can share your thinking on chat. Some of you've already started, and also by using the hand symbol and I can see Mary's already goes up. I think we're all quite familiar now with using zoom and using these functions, but it means that we can have a conversation on two levels, people speaking and also in the chat. So I will immediately start with Mary since her hand was up first.



Professor Mary Mittelman

Professor of Psychiatry and Rehabilitative Medicine, NYU School of Medicine

What I think is also something we should think about is what is the underlying principle with all of these psychosocial interventions? What is the theme? And I think for me, anyway, the theme for the interventions I've been involved with, which have included interventions for the person with dementia and for the dyad, is social support - one way or another it's formal and informal support. That was pointed out to me actually by a CNN reporter, when she was asking me about The Unforgettables, which is a chorus



Dr Lee-Fay Low

I agree with Alison's point around co-designing programs with people with dementia. I think that we as researchers need to examine our own stigma towards people with dementia and whether we can share status with people with dementia as co-researchers.



Paola Barbarino

This is a great discussion, sorry to have to leave. It has been great to see so many familiar faces. Ciao Paola



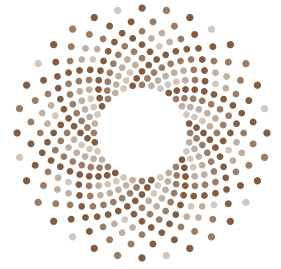
Dr Elaine Wiersma

Yes, Lee-Fay, I completely agree. We need to be reflective on our own practices.



Professor Bob Woods

In response to George, I agree that an important aspect is to enable people



that we founded in New York that's been, until the pandemic performing regularly with people with dementia and their family members since 2011. And I think, there again, the support of the chorus members for each other, for the people with dementia, for the family caregivers and from the audience providing support, when they enjoy the concert; that's again, social support.

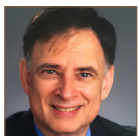
The original intervention that I founded, the NYU Caregiver Intervention also was based on social support. And I think most of the interventions that we've been talking about today, really the fundamental theme is how to improve the support, the social support, which then results in a feeling of wellbeing, however, we define it or measure it for both the person with dementia and for the family.



Professor Anthea Innes

Professor of Health Aging and Society, McMaster University

Yes, those are all really important points, Mary and I, when I visited your choir, it really was an unforgettable experience and influenced other work that I went on to do in the UK, and it really does it doesn't just impact on the personal events, dementia, and their care partners that impacts on those who, who view the performance. It's really a quite powerful, medium. I can see that Joel has his hand up.



Professor Joel Sadavoy

Professor of Psychiatry, Faculty of Medicine and Institute of Medical Sciences, University of Toronto

Thank you. It's a pleasure to see everyone and to be here. As Mary mentioned my work in Ontario, Canada has been in the area of providing dementia services through family caregiver support programs developed at the Reitman centre for Alzheimers Support and Training. The development of such programmes is challenging, particularly creating models for scaling them from theory, to practice, to broad system impact. I believe that scaling strategies are critical foundational underpinnings of dementia care beyond providing direct support for caregivers. Some key elements to enable caregivers to continue to sustain themselves include specificity of support, that is knowing and addressing what the caregiver requires for their particular situation, and delivering programmes that address each caregiver's specific needs. both to support them and to develop their caregiving skills and capacities. These basic elements constitute some of the underpinnings of the programmes that I've been involved with in Ontario. Scaling includes a number of key factors, which we're all aware of. For example, programmes for caregivers must be accessible and easily available in the locale in which caregivers live. To move from a centralised programme to a broadly disseminated programme means developing a network of partners to move out into the community.

Such partnerships such as the Ontario model, can integrate community programmes with centralized programs in universities or hospitals, where a lot of the innovative, developmental research work is going on. Scaling also requires stable funding. To rely on grants or research funding means that programs may continue on grants only to

living with dementia to retain their place in the community - to attend and participate cultural events, to continue at the gym or whatever - this is part of our Dementia Friendly community movement, rather than having special activities in care facilities.



Professor Allison Lindauer

Excellent point Lee-Fay Low about recognizing our own stigma, similar to recognizing our own racism.



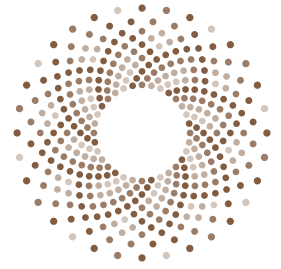
Professor Sandra Black

Sandra to everyone. If possible I would like to bring out the issue of Medical Assistance in Dying which is now more available in Canada.



Professor Brian Lawlor

To Mary and Bob and everyone, Do need to develop specific interventions around dementia caregiver



fall off the radar because the funding ends. So we view government participation in funding as critical. In Ontario, a jurisdiction of about 14.5 million people, the provincial government has funded a province wide, disseminated programme called Enhancing Care for Ontario Care Partners (EC program). This is base funding flowed through Sinai Health, an academic health sciences centre, for a program that is provided free to dementia family caregivers across the province.

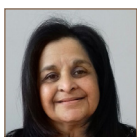
The funding was established 4 years ago to sustain an evidence-based set of interventions called CARERS. A challenge to any such program is maintenance of fidelity to the model as it is scaled. Training and maintaining fidelity to an evidence based model I believe are important and need to be embedded in scaling strategies and so beyond simply initiating a network of delivery sites, this program funds and provides manualized training and ongoing mentorship to all clinicians delivering the program in the province. Concurrently, successful scaling requires leadership which we have found requires a sensitive balance between encouraging the partner organisations to develop a degree of autonomy in their own region for the development of their programme while maintaining fidelity to the program model and mandates. . Our Ontario model therefore includes a hub and spoke model of collaboration, i.e. semi-autonomous partner sites guided by a formal MOU relationship to the central leadership site at Sinai Health . These are some of my thoughts about scaling which build on what Bob said about translating everything we know into reaching the people who need the help.



Professor Anthea Innes

Professor of Health Aging and Society, McMaster University

Yeah, there's a couple of questions or similar comments in the chat about how we extend activity beyond universities and healthcare environment so that we can sustain those changes? That's a really nice example for policy linked there. Thank you. Esme was the next person to have her hand up.



Professor Esme Moniz-Cook

Professor in Psychology Ageing & Dementia, University of Hull

I just want to make a couple of points as I'm very, very pleased that Bob picked up on some of the outcome measures issues, because I think we need to broaden our approach to measurement of psychosocial interventions in dementia care research.

1. Funded randomised controlled studies of psychosocial interventions were emerging in 2004 when we began systematic consensus -based work to chart outcome measures that could be used in for both research and routine practice. This was published in 2008 and it still widely used¹. Unsurprisingly many of these measures had been used in well- funded pharmaceutical studies and tended to focus on deficit related paradigms and outcomes such as neuropsychiatric symptoms, cognition, mood, ADLs. Quality of Life measures were broadly defined and it has been hard to demonstrate effectiveness in many high quality psychosocial intervention studies. Bio-psychosocial approaches to support have

(both emotional & social) loneliness?



Professor Bob Woods

Lucia - agree intergenerational work is so important - it's an area of practice that is ahead of research - can be young children or teenagers - and great for reducing stigma too!



Dr Eamon O'Shea

We also need to investigate how the public value various services and supports. WTP and DCE experiments can help in resource allocation decision-making by providing estimates of citizen's willingness to fund different psychosocial programmes. Economics and costs matters for good priority-setting. So too does information to the public on what matters, even if the information is not always consistent or definitive.

helped us in some ways to understand how delay distress in dementia care, but perhaps we now need to move beyond the constraints of deficit - based outcome measurement.

2. Some three decades on... we have moved to new ways of thinking about what is important to people and families reflecting an asset-strengths approach to outcome measurement. There are many emerging socially -based interventions developing that people with dementia themselves can contribute to. For example if we are devising a music or arts based intervention - where people are clearly enjoying themselves 'in the moment', it makes no sense to use broad based retrospective quality of life measures that don't actually capture the experience or 'enjoyment'. Focussing on asset -based outcome measures of well- being to capture the concept of a given creative intervention is perhaps one of many ways we can balance out deficits vs assets in research about people with dementia, families and those that provide support. Work on measuring concepts of joy, flourishing, hope, spirituality and other positive psychology approaches to intervention and its measurement may counteract the double stigma of age and dementia.

Ageism remains one underlying driver of fear and loss of mind the other, in the narrative of dementia. As we grapple with this and economic narratives, humanistic and existential philosophies still found in some ethnic groups may be of interest. Here we can find care for elders sometimes with few resources apart from love. I hope the funders of dementia care research going forwards, will draw from what we know so far and support novel approaches to examining what difference we can all make to the lives of people and communities.



Professor Anthea Innes

Professor of Health Aging and Society, McMaster University

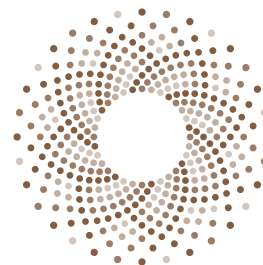
Okay Esme. I'm reading the chat there as well, just to see if any points can be included here. I've noticed that a couple of people have been talking about how to read grid, marginalised groups as well within psychosocial research to make sure it's not just the same people who benefit from initiatives and interventions at different points in time. I can see Dianne and Kristen have both been talking about up to anyway. Please feel free to keep contributing to the chats as well, because I'm trying to read the chat and listen. So do continue the conversations in the chat too, and I think the next person I sort of have the hands up, Alison.



Professor Allison Lindauer

Assistant professor, OHSU's Layton Aging and Alzheimer's Disease Research Center

Hi, I'm Allison Lindauer. I'm with the Oregon Alzheimer's Disease Research Center and my research focuses on adapting Linda Teri's STAR-C program to a tele-health type intervention. So I'm grateful to hear the comments from Bob about continuing the work instead of recreating the wheel. The one concept that I feel that it's important to examine in families, both the person with dementia and the family members is the



George Vradenburg

Agree with Mary. We have a 3000 person closed FB group for PLWD and caregivers. Lots of sharing. Lots of mutual support.



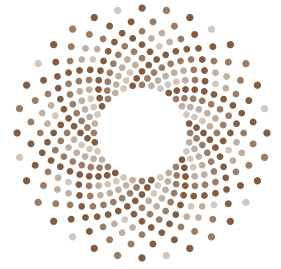
Professor Mary Mittelman

It is also important that we recognize that dementia may impair some areas of function, while others are spared. For example, a former lawyer who came to a photo workshop at our NYU Family Support Program and discovered he was a very talented photographer, which enhanced his sense of self worth and his wife and he enjoyed several years of walking around New York while he took beautiful photographs he was able to exhibit.



George Vradenburg

Those without dementia also have a wide variety of



concept of pre-death grief. The grieving experience that comes with learning about the diagnosis for everybody in the family, and then the , the gradual loss process for everybody involved. We know that grief and burden and depression are closely intertwined. Marwit and Meuser has have indicated it's a very important concept for families. And when we don't address grief, the outcomes after death are negative as well. So that's just my 2 cents. I'm very grateful to be here. And I want to thank Dr. Werner and Dr. Mittelman, lovely to hear the important conversation.

capabilities and interests. PLWD and their caregivers are people too.



Professor Anthea Innes

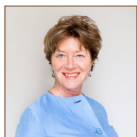
Professor of Health Aging and Society, McMaster University

Okay. I'm going to move to Myrra now.



Professor Esme Moniz-Cook

Have people done anything on methods to define and understand dementia as a social construction and ways to build positive attitudes? Dementia friends may not pick up the notion. Agree with Laura - some people in some countries shy away from diagnosis in the very old and look after elders as wise people who need to be loved



Professor Myrra Vernooij-Dassen

Professor Emeritus, Radboud University Medical Centre

Thank you. I enjoyed Mary Mittelman's talk with familiar information, as well a new insights. I want to emphasize that social interventions should not only include social support. A comprehensive concept on social aspects in relation to health is social health. This concept indicates how people relate to each other and influence each other. Social health is not only about social support, but also about how persons allow other persons to use their capacities. Meaning to allow people to do what they still can do. Rather than focusing on helping people, allowing people to contribute might be more effective in boosting well-being.



Professor Anthea Innes

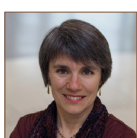
Professor of Health Aging and Society, McMaster University

Thanks. Yes. I've found your, work on social health really useful when we've been looking at the impact of different initiatives on people who have dementia and their carers. And I think it's, it's gaining more and more in currency that approach. And it's a really valuable addition and people are talking here about how to expand beyond individualistic approaches that you're taking some more structural considerations too. Can I move on to Alison Phinney now?



Professor Dawn Brooker

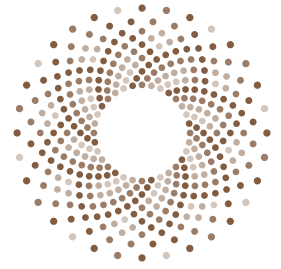
<https://adsdementiablog.wordpress.com/2021/04/08/sci-dem-resources-what-are-they-and-why-should-i-take-a-look/> We have done a realist review on what makes community interventions



Professor Alison Phinney

Professor, School of Nursing, University of British Columbia

Hi, thanks. I think one idea that is important to get on the table here is the place of people with dementia themselves. We're doing work here in British Columbia, on the west coast of Canada and together with partners in Ontario working in community



settings, and you've already commented on that in, in the chat. But in a really important part of this work is conceptualising it as not doing it for people with dementia, but doing it in partnership with them. And it has been a game changer in a lot of ways. And I think it is important from a social equity or an inequity lens from a social justice perspective. But it also, I think it, what we see as it's just working better. And I'm thinking about the, the presentation, with the really important ideas we heard about stigma and that education itself is not enough to fix it.

But I was really struck by how our, the community organisations who are wanting to do something for people with dementia gets stuck at the idea that I don't know enough. I need to know more education will make it better. And what we found is what, what seems to get beyond that is bringing people with dementia into the, in this case, the virtual room, and people talk about the penny dropping about suddenly it kind of makes sense. They gain confidence, they gain knowledge about how to engage with people with dementia. And so we haven't measured it, but I might expect that the stigma has decreased. The people are actually starting to, to make good working relationships together with people with dementia, moving forward, to create the kind of programmes that people want.



Professor Anthea Innes

Professor of Health Aging and Society, McMaster University

Yeah. I agree with you. It's so important that we involve people with dementia and work alongside them in terms of design and what might work for them so we can work out how it works and why. And I can see there's some agreement there on the comments you've made there in the chat as well there. Thank you Lucia, I'm trying to get through as many people as possible who have their hands up. So the next person is Lucia.



Dr Lucia Crivelli

Head of Neuropsychology at FLENI, Buenos Aires, Argentina

Well, yes, I'm the second (indistinct person) from Argentina. I wanted to mention an intervention that we did here in Latin America, in our country, in Argentina. We designed problem [inaudible] high school students with MCI patients who were under cognitive rehabilitation and because of the pandemic, this treatment was interrupted. So we wanted to continue the treatment through tele neuropsychology. And this was very difficult, because patients didn't know how to use the computers. So we made partnership. We talked here before somebody talked about making partners with a high school, and students who belong to a community service programme volunteered to help remote [inaudible] to use their computers.

So they had four encounters together with a teacher, and they had contact with patients with MCI and MRI and dementia and taught them how to use the computers in order to receive afterwards the cognitive rehabilitation. We measured ageism and before and after in the student group we noticed a big change as students had changed completely

for people with dementia sustainale over time. 3 really user focussed books available on this blog site



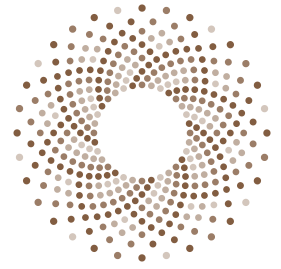
Dr Eamon O'Shea

Choice, autonomy and engagement in dementia are influenced by income and wealth differences - need to take income into account more in psychoosocial models



Dr Lee-Fay Low

Laura, absolutely agree around understanding tailoring and cultural adaptation. What are 'core' components of interventions? Also agree around stigma in health care professionals - in GPs it's a massive barrier to diagnosis that we've thinking about how to intervene with.



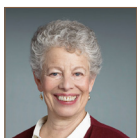
their perspective and their prejudice on this population. And of course, we mentioned wellbeing in the journey and they found this experience very rewarding and the time connected to the computer increased. No, definitely. So I think that, for example, this intervention has the definition of fact of connecting generations and generations that have been separated during the pandemic. The pandemic been strikingly damaging of their relationship between grandparents and grandsons and the generations that are far apart. And that this is an important thing to do because we know that the young people are the ones who in the future, we will change the perspective we have on dementia and the stigma. So I wanted to bring something to the table.



Professor Anthea Innes

Professor of Health Aging and Society, McMaster University

Brian Lawlor has just posed an interesting question on the chat to Mary and Bob in particular. Do we need to develop specific interventions around dementia caregiver for emotional and social loneliness? Will Bob or Mary, like to respond to that point?



Professor Mary Mittelman

Professor of Psychiatry and Rehabilitative Medicine, NYU School of Medicine

Yeah, well, I'm actually, this is relevant. I saw in our family support programme, I started, I run it partly, partly because of the way the state tells me to, and partly the way the clients asked me to. And so we started what we call a Kaffeeklatsch, which in German, I think, was a place to gossip in the coffee house. Ours is online and for the caregivers, it has become incredibly popular.

People come to it in order to be with other caregivers. And we don't have a social worker running it, they hang out together as they might've been in a German coffee house. And it seems like just based on, you know how many people come, it is one of our most popular activities. And then people ask, well, can we have each other's email addresses so we can meet, in smaller groups or in pairs, all online. And I think that this, this kind of speaks to the loneliness that they all talked about. And the fact that because of stigma, many of their friends left them, so they are on their own, and then of course the pandemic isolated them further. And I think just watching the numbers of people who come -- it started being a one time thing as an experiment, we're now doing it several times a month at different times of the day, because people asked for that. And I think if we had the resources, we'd be happy to have the Kaffeeklatsch open all the time. So I think that does speak to loneliness and isolation, and it's a very low cost intervention that we're planning to study, and in the near future.



George Vradenburg

Is there anything to be learned from persons and families with intellectual, developmental or physical disorders and disabilities?



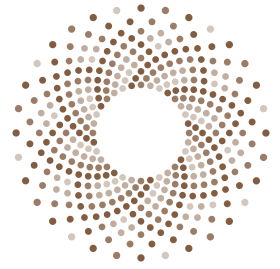
Dr Aimee Spector

There are many more positive outcome measures emerging, e.g. The EID-Q which is a measure of engagement and independence, completed by the person with dementia.



Professor Kristen Jacklin

Our work with First Nations in Canada and Indigenous populations in the US demonstrate a different understanding of dementia and the traditional Indigenous knowledge held in these communities hold the key to limiting stigma at various levels



Professor Anthea Innes

Professor of Health Aging and Society, McMaster University

Yeah. Thanks Mary. There's a couple of comments agreeing with what you're saying there in the chat too Nancy. You've had your hand up for a while.



Professor Nancy Hodgson

Claire M. Fagin Leadership Professor and Chair of Biobehavioral Health Science, University of Pennsylvania School of Nursing

I'm really grateful for this opportunity to join the conversation. I want it to pick up on a point that Joel made around the need for more specificity regarding scaling interventions. Laura Gitlin and I recently completed a review of the literature on scaling caregiver interventions. We focused on dementia caregiver programs that have been implemented in real world practice settings. We brought an 'implementation science' lens to see what generalisable lessons we could learn from caregiver interventions that had been scaled, such as the NYU CI programme and the Star C programme. We sought to understand "what" works in these programs in terms of their active ingredients- for example, social support. We also to understand "for whom" interventions work since we increasingly recognize that not all programs work for all subtypes of dementia and marginalised communities have often been excluded from trials. Finally, we sought to understand "by whom" these programs work in terms of the workforce needed to deliver these interventions.

Our first lesson learned was that while attention to fidelity is important, it was the adaptability of the programme that led to its uptake in the real world, or not. In other words, the flexibility of the program to adapt to local contexts drove successful implementation. The second major lesson we learned was there has been little, if any, attention to the sustainability of these interventions. What we still need to understand to sustain any program scaling is attention to costs such as the cost of training the workforce, and the cost of monitoring clinical outcomes of importance. Thank you.



Professor Anthea Innes

Professor of Health Aging and Society, McMaster University

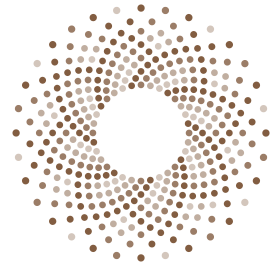
Thank you. That was a nice summing up with some, some of the points in the chat . You mentioned your colleague, Laura Gitlin. She also has a hand up. I'm not sure if it's a link point or, but we will move on and see what you, what you wanted to say.

and facilitating community and family care. These are culturally grounded, values based knowledge systems. When we present these findings to mainstream health care workers there is always someone who observes how helpful the non-biomedical understanding of dementia can be to approaches to care. There is much to be learned cross-culturally.



Professor Esme Moniz-Cook

Agree with Laura - yet our times of joy moments a few and far between but important to keep me going - sustainability may be about examining moments of joint pleasure between people and those they interact with - perhaps we should follow people over with interactive video material.



Professor Laura Gitlin

Distinguished Professor and Dean, College of Nursing and Health Professions, Drexel University

Yeah, no, thank you. And I'll be brief, but I just had a few reflections on a number of points that were made and I don't want to be redundant, but Esme really made all the points I wanted to, but said it's so elegantly. And I thank her. And I think really, I just want to emphasize several things. One is we, have a tremendous foundation of, I think Dr. Wood said, you know, 60 years of research, but in that respect, the glass is half full, but it's also half empty. We really need new models of psychosocial understandings, if you will. That also include the environmental context as Dr. Woods pointed out. And the other point, it really builds on Dr. Woods. I raised my hand way back then. I wanted to say essentially Dr. Woods a very important top raises the issue of what should we measure and why we need to be very clear and then link that to our interventions.

And what's important across the journey of, of dementia. So what we measure and why at any one stage really has to be clearly delineated and we haven't necessarily done that. What's important to people living with dementia and their caregivers and what matters in early stage, for example, maybe very different in the severe stages. And therefore, what do you know, how do our measures differ? One of the important points of having this global round table is that it brings the issue of cross cultural validation, right front and centre. And then back to Dr. Wood's point of tailoring what matters because what matters in one country and within one country, one geographic region. And within that do you know, one group versus another can be very, very different. And we now have, you know, approaches to tailoring our measures to what matters using goal attainment, scaling for example, and other approaches coming out of psychology. And there's a whole array of I'll call it psychosocial environmental concerns that have not been developed as measures.

Engagement is very critical at different stages for people living with dementia. For example, we've talked, Dr. Perla gave a great talk on stigma. For example time for self. We find to be a huge issue for caregivers and as an important measure. We've heard from people living with dementia, through various focus groups, they want to know why are we focusing only on deficits? And where's the strength based approach such as understanding adaptation and how people at the early stage adapt to stigma, for example, and to a diagnosis. And then to, with still having insight in terms of changes. We've also heard from focus groups, with people living with dementia to really better understand behavioural symptoms and its impact on people living with dementia themselves. And then in another two points I just want to make quickly is we hold our psychosocial environmental interventions to a very high bar.

We want the outcomes to last forever. And so the question is how long do our effects last? And isn't it good enough to provide engagement and to reduce anxiety and agitation in a person living with dementia for a short period of time. You know, I take an aspirin when I have a headache and I don't expect it to last more than four hours, and then I may take another, but we also, we often you know, here in terms of translation and implementation, like how long is this intervention going to last and then is it worth it? So I do think that looking at multi-component and complex models of quality



Dr Gustavo Sevlever

We can learn a lot. Empathy. Kindness. Different views. Human relationships. Compassion. The need to understand. The benefits of understanding.



Professor Mary Mittelman

Assuming cognitive decline is a necessary consequence of aging is an impediment to early diagnosis



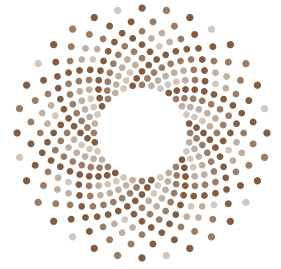
Professor Esme Moniz-Cook

Unless we all learn to cover up our cognitive decline as we age and concentrate of saving our reserve for things we want to do



Professor Joel Sadavoy

In many countries the majority of caregivers of persons with dementia are employed and balancing



of life that are multi-domain Nancy Hodgson, and I have a book about this is a very helpful framework to help identify different quadrants that are important in the disease progression to both the person living with dementia and the family caregiver. And then just one other point, and that is back to Dr. Perla's stigma.

I want to add that there's tremendous stigma among health professionals. And when we look and understand stigma from the time of relaying a diagnosis, which there's still fear of relaying a diagnosis. To having helped providers work with people, living with dementia in the medical setting, in the community-based setting, often their own stigma, overshadows their ability to provide the best evidence and a person centered care. So those are the points I wanted to make. And I want to thank you very much.

family work and dementia care. Engaging business and employers in understanding and participating in sustaining dementia caregivers is important strategy. It is economically in the interest of business as well as the caregiver employees.



Professor Anthea Innes

Professor of Health Aging and Society, McMaster University

That's a lot of interesting points there and lots of related chats in relation to what you were saying, we've got time for one more question. One more contribution speaking, before we hand over to Hilary, a person living with dementia for her to draw together, some of her observations of the dialogue. So Howard.



Professor Howard Bergman

Professor of Family Medicine, Medicine (Geriatrics), and Oncology, and Assistant Dean, International Affairs, Faculty of Medicine, McGill University

Thank you very much for this wonderful, very important discussion. Just very briefly, it strikes me as a member of the Council and as someone who's been following the various dialogues that we are still working in silos. We have the basic science research, the drug development, health service, health policy implementation, social/psychosocial. I'm sort of making a call now, very briefly, to ask how can we develop a more integrative approach to research in dementia and to clinical care in dementia.

And from the point of clinical care, we've always had a problem in our clinical care of bringing together different cultures of medical and social interventions. So I think this is something that we can think about and perhaps for an eventual dialogue of the World Dementia Council thinking of how we can bring the various disciplines together. We see it in some of the prevention trials. I'll stop there. Thank you very much for this wonderful discussion.



Professor Esme Moniz-Cook

Hilary has brought together the key points so well - she has demonstrated that a person with a diagnosis can lead us in new pastures



Professor Dawn Brooker

Thank you Hilary



Professor Sandra Black

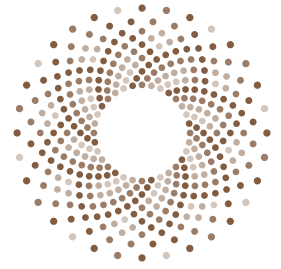
Professor of Medicine (Neurology), Sunnybrook HSC, University of Toronto

Though there is no time to discuss today, I want to mention a new development in Canada as of March 2021 around death with dignity, namely the option for Medical Assistance in Dying (MAID) even if death is not foreseeable within a few years. (See



Professor Arlene Astell

I think Mary's point about demonstrating cost-benefit analysis is critical as there are major challenges to getting evidence-based interventions out of the lab/off the page into services.



<https://www.justice.gc.ca/eng/cj-jp/ad-am/index.html> for requirements of consent, adjudication by two physicians/ nurse practitioners etc.) With advances in fluid and imaging biomarkers confirming brain neuropathologies in Alzheimer's Disease and other dementias, because treatment options lag behind biomarker profiling, MAID is becoming a pragmatic consideration in clinical care and also inadvertently sometimes in the screening process for double-blind clinical trials, which provide these biomarkers.

Arising in part from stigma and fear of loss of autonomy usually in high functioning individuals, including health professionals, confirmation of the neuropathology in vivo has prompted some to set in motion planning for MAID. Hence, it would be valuable to discuss this topic and compare approaches in different countries.



Professor Anthea Innes

Professor of Health Aging and Society, McMaster University

There's also the opportunity. It's out a bit more in the chat in the next 10 minutes as well. People want to raise any other points, but I would like to know hand over to Hilary, who is a person living with dementia for her to share her thoughts on, on what she's heard in the dialogue today.



Hilary Doxford

Former Vice Chair, European Working Group of People with Dementia, and Ambassador for the Alzheimer's Society speaking nationally and internationally as a person with dementia

Thank you, Anthea and hello everybody. Right. Well, I'm feeling much happier now than I was an hour ago, primarily because I've heard so many points from you all that I totally agree with. And it reminded me of just how much work's going on and how, how hopeful the future is for people with dementia. I'm going to be jumping about a bit because I can't formulate a coherent sort of response in the moment anymore. But when I was diagnosed back in 2012, my thoughts went straight to the end point of dementia and I was thinking my God, I don't want to live in fear and pain and not be able to communicate that pain. As time has passed over the intervening years, I have learned so much more about dementia.

I think the points to be made about the progression of the disease and how you need to look at each disease stage differently is very relevant, because I've, you've made me look back and think. And eight years ago, when I was diagnosed, my primary focus was on keeping my cognitive function scores as high as possible. Now I couldn't care less about them really. Now I want to live in a place where I don't feel frightened, where I feel supported, where I feel happy and my quality of life means so much more than the objective measures that many people use. So I've moved from objective targets to subjective aspirations and I've learned to let go, and I think as a person with dementia, you really need to learn to let go. I'm not saying give up trying, but you have to recognise that there comes a point when you cannot do something any longer, and it's much better to let it go and I like what you've been talking about as it is about enabling and working with, not focusing on deficits and doing for. Thank you. Yeah. Focusing on the positives

This is particularly so when services are managed through healthcare, for example in UK where the NHS is so stretched and unable to provide staff training or opportunities for offering new interventions. I have been building implementation into interventions we deliver in my work in Canada where we train the staff as we are collecting our research data but this is totally reliant on the existence and duration of the research funding. Who will pay for this once that ends is always a major barrier.



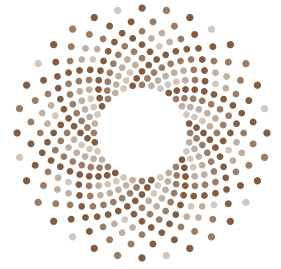
Professor Joel Sadavoy

Well said Arlene



Professor Vanina Dal Bello-Haas

Thank you Hilary for your perspectives.



rather than deficits. I mean, so much more, it's such a positive experience. Sorry. I'm jumping about a bit and not, probably not particularly coherent. What else did I want to say? The person that talks about the humanistic models I like, I really liked the sound of that.



Professor Anthea Innes

Professor of Health Aging and Society, McMaster University

That's okay. The conversation has jumped about a lot, so you've done very well to bring together the key points for you there.



Hilary Doxford

Former Vice Chair, European Working Group of People with Dementia, and Ambassador for the Alzheimer's Society speaking nationally and internationally as a person with dementia

Okay. I think I'll just say so many initiatives and good ideas. Again, people were talking about why are the good things only happening in some places, why are they not being shared? We've got Boris Johnson over here talking about levelling up the UK, meaning everybody gets equal opportunity, equal financing. And that's what we need to do with dementia. If you've all done such good work, you've got so many good ideas, great initiatives then why, why doesn't everybody get access to them? I've got friends who I wish could stand in my shoes because I know so much of what you do, it makes such a difference to me. They haven't a clue of just how much work is going on around the world to make their lives better. So long may you all continue I thank you for your tenacity and your passion because without it, my world and my friends' world would be a much darker place. So thank you very much.



Professor Anthea Innes

Professor of Health Aging and Society, McMaster University

Thank you Hilary. That was incredibly helpful. Bringing the discussion together. I'm now going to hand back to Professor Wang for her to make a few concluding comments.



Professor Huali Wang

Professor and Chair for Clinical Research, Director of the Dementia Care and Research Center, Peking University Institute of Mental Health

Thank you very much. Professor Innes, and also thank you very much, Hilary, for your insightful personal experiences. How our psychosocial research would benefit for the person living with dementia and also for the family with a person living with dementia? That's a very important point. We have wonderful opening presenting and also we have very, very important interactive discussions about how we can improve our psychosocial research to improve an outcome of persons who deal with the issue and also their family.



Professor Myrra Vernooij-Dassen

Thank you Hillary. You are very supportive to us as researchers. Very encouraging



George Vradenburg

Love you, Hilary



Hilary Doxford

I didn't mention that I agree that the family care giver needs as much if not more support than the PWD



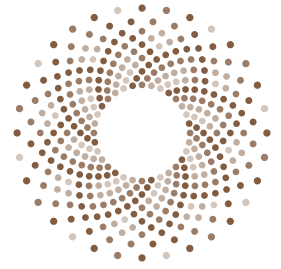
Dr Gloria Wong

Thank you so much Hilary. Your words are great reminders for us what is important in dementia care and intervention research.



Dr Aimee Spector

Thank you Hilary for such a great talk.



Mary has shared her experience of 37-years work, how she has built an NYU CI project and also how she has moved forward to make it implemented in New York state. So that's very important. That is a great achievement, congratulations.

Professor Werner has shared her perspective on how we can realign dementia that is so widespread all over the world. Also she shared some initiative how we can overcome stigma as part, or just measure it in the discussion part. She mentioned that Alzheimer's Disease International has published a report on stigma over dementia. Also last year, I remember that if I'm not wrong, the theme of world Alzheimer's month is Let's talk about dementia. It has opened wide discussion about how we can understand dementia, how we can make it understandable in the society, and how we can help the people living in the society to live much better.

Professor Woods, has shared his experiences on his insight into promoting psychosocial research in the field. I think that's very important, although we have talked about different initiatives worldwide, still, there are some barriers. We have not successfully translate our findings of research into practice as lots of experts have discussed. For example, we have not reached great consensus on what we can do. I mean which components might be helpful, how we can integrate them to make it a multicomponent psychosocial intervention that could be scaled up in different cultures in different settings worldwide, and regarding the outcome, how we can measure the effects of psychosocial social intervention either for caregivers or for persons living with dementia. We still need a lot of work to improve this: how we can reach consensus on outcome measurement, whether it's cognitive function; how we can preserve their capacity; how we can prevent the deficit of some functions. We still have a lot to do and try to improve this area to move psychosocial management and psychosocial research forward.

We have discussed a lot about different aspects but still we think that there are some insights. I remember there's one important point about social health. Myrra mentioned that social health is very important. In recent years, social prescribing has been applied in different aspects of health promotion. Probably currently there's some necessity for us to think better. Social prescribing might also be helpful for us to implement psychosocial intervention for persons with dementia and their family. So, I thank you very much for a wonderful presentation and lively discussion on this field. I think that we can work on it together in the future to move psycho social research for people living with dementia and their family forwards. Let's work together. Thank you very much. Now I'd like to turn back to Lenny for his last comment.



Lenny Shallcross
Executive director, World Dementia Council

Right. Thanks. So I will say something in one second, which is thanks very much, and we'll be back in touch with the transcripts and it's going to hop past the hour. So time's up. Have a great day. Thank you for taking part and making such a lively discussion. We'll be back in touch. Thanks folks. Have a good day, evening, morning, wherever you are in the world by.



**Professor
Esme Moniz-
Cook**

We have submitted a grant to the NIHR on social prescribing - lets hope the fund



**Professor
Rose-Marie
Drees**

Social health is important, but emotional health is certainly as important! It is all about adaptation

The World Dementia Council (WDC) is an international charity. It consists of senior experts and leaders drawn from research, academia, industry, governments and NGOs in both high-income and low- and middle-income countries, including two leaders with a personal dementia diagnosis. The WDC has an executive team based in London, UK.

worlddementiacouncil.org

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