LEE LI MING
PROGRAMME IN
AGEING URBANISM

Collaborating through Research for Dementia in Europe

Ageing, Dementia and Technology[1]

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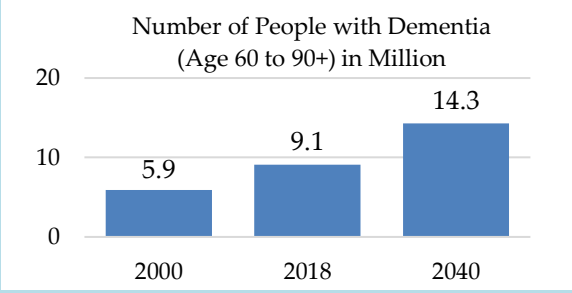
Europe's Efforts to Scale Up Dementia Research

According to the World Alzheimer Report 2015, the population living with dementia (aged 60 and over) across Europe is projected to increase to 14.3 million by 2040 (see Box 1). [2]

Box 1: Projected number of people with dementia and prevalence of dementia increases in Europe



Source: European Union. (2018). Health at a Glance: Europe 2018 State of Health in the EU Cycle. OECD Publishing, Paris. doi: 10.1787/health_glance_eur-2018-en.

[1] This is an evolving database. We will be adding more examples and cases over time.

[2] Prince M, Wimo A, Guerchat M, Ali G-C, Wu Y-T and Prina M. (2015). World Alzheimer Report 2015. Retrieved on January 21, 2021, from http://www.alz.co.uk/research/world-report-2015.

The societal cost of dementia is high, estimated at 103 billion euro in 2005 and expected to increase to over 250 billion euro by 2030.[3] Since 2007, the European Commission has increased research efforts on neurodegenerative diseases including Alzheimer's disease in the European Union (EU) Health Strategy. Collaborative and translational research is emphasised, with a specific sub-agenda on human development and ageing as well as the brain disorders such as dementia.

This web post note reviews and uncovers some of the collaborative partnerships in research that help to shorten the time taken to identify key research gaps and increase opportunities for dementia innovation.

Advancing Dementia Care through Research

Supported by three organisations (Emmaus Elderly Care and Residential Care Holy Heart in Belgium, and ZorgSaam in the Netherlands) implementing dementia care programmes in Europe, a scoping review of the unmet needs and gaps in delivery of dementia care by Martin et al. (2018) uncovered reasons for poor communication and information sharing on dementia care. The lack/limited knowledge of local service provisions and fragmented pathways for carers in achieving person-centred care led to ineffective healthcare strategies and policies.

With the recent development of technology, greater interconnectedness across the globe is possible. This enables large consortiums across borders and fields of study to come together and work in the digital space (Bottanelli, et al., 2020).

While technological innovation could undeniably improve the lives of persons living with dementia (PLWD) and their carers, technology can also help to promote greater research outcomes by tackling the issues of fragmentation in care approaches upfront. This includes business models as well as enabling social care authorities, healthcare sector, hospitals, research centres, private companies, and other stakeholders to innovate through digital information sharing and data interoperability.

Developing a strategic research agenda

Unsurprisingly, the work plan adopted by Alzheimer Europe's in 2021 shows Europe's resolution to place dementia research as a priority. Hence, one of its key core activities is to examine the application and role of technology in understanding dementia (see Box 2).

[3] Wimo, A. and Jonsson, L. (2009). Cost of illness and burden of dementia in Europe: Prognosis to 2030. https://www.alzheimer-europe.org/Research/European-Collaboration-on-Dementia/Cost-of-dementia/Prognosis-to-2030. Accessed 7 Mar 2021.

Box 2: Research is Key in Alzheimer Europe's Work Plan

Alzheimer Europe's 2021 Work Plan outlines the following core activities:

a. Providing voice to people with dementia and their carers
b. Making dementia campaign a European priority
c. Promoting a rights-based approach to dementia
d. Supporting dementia research and continuing the development of the European Dementia Observatory on research and inventory
e. Strengthening the European dementia movement.

Source: Alzheimer Europe. (2020, December). Europe's 2021 Work Plan. Retrieved on January 21, 2021, from https://www.alzheimer-europe.org/Alzheimer-Europe/Our-work/2021-Work-Plan.

With technology, interdisciplinary research teams can collaborate more easily across countries. This way, they can establish reliable findings on the efficiency of internet-based interventions in improving carers' self-efficacy in managing challenging behaviours and day-to-day challenges caused by the condition of PLWD.

Channelling funding to support agenda

To show how technology can improve the lives of PLWD, the Interdisciplinary Network for Dementia Using Current Technology[4] (INDUCT) was set up.

Funded by the Marie Skłodowska-Curie Innovative Training Network, INDUCT works closely with Interdem which is the largest network of psychosocial research for PLWD (Box 3). INDUCT provides Early-Stage Researchers with opportunities to acquire knowledge and skills needed in their work on dementia and technology. Interdem, on the other hand, provides the linkways to a network of researchers and practitioners/clinicians for institutional collaboration and intersectoral movement in early detection and timely intervention.

[4] Interdisciplinary Network for Dementia Using Current Technology. (n.d.). About INDUCT – The multi-disciplinary, inter-sectorial educational research network. Retrieved on January 21, 2021, from https://www.dementiainduct.eu/about/.

Box 3: Consolidation of Fragmented Research Studies by Supporting Inter-Disciplinary Collaboration/Expertise

Interdem's strategies and five key activities:

a. Annual conferences/meetings to support new research,
b. Symposia at European conferences,
c. Collaboration on pan-European grant applications and publications for high-quality European research, and
d. Research capacity built through collaborative PhD projects and student exchanges.

The active research network spans across 18 European countries, 63 research centres and 84 members from different disciplines, including:

a. Medicine (psychiatry, neurology, geriatrics, general practice and medical ethics),
b. Psychology/ clinical psychology,
c. Nursing, Medical sociology,
d. Occupational therapy, music therapy, physiotherapy,
e. Dietetics and social work.

Source: Moniz-Cook, E., Vernooij-Dassen, M., Woods, B., Orrell, M. & Interdem Network. (2011). Psychosocial interventions in dementia care research: The INTERDEM manifesto. *Aging & Mental Health*, 15 (3), s. 283–290. doi: 10.1080/13607863.2010.543665.

With the collaboration, Interdem can look into research cost-effectiveness of care pathways, psychosocial interventions, end-of-life strategies, and educational programmes. Interdem also enables easier collation of evidence and shorter meta-analysis of dementia research.

Promoting collaborative research projects on neurodegenerative disease

Dementia-friendly communities can function more effectively by applying the recommended findings from research studies conducted through collaborative partnerships (Williamson, 2016). This can happen through understanding the direct needs of caregiving, commonalities across local municipalities as well as the types of care services and users' demographics. The consolidation of fragmented research studies supported by inter-disciplinary teams with different expertise plays a significant role in this process.

For example, there has been a growing number of support programmes scaled up by technology, e.g., online training and interventions. A systematic review on internet-based interventions by Egan et al. (2018) found that there was some evidence to the benefits of such interventions in improving carers' mental health. However, findings in systematic reviews could become obsolete in the future due to the time span of dementia research and speed of advancement in technology. This highlights a crucial research gap in which the author suggested one pragmatic solution to plug it – developing an online repository of past and ongoing efforts for machine learning to analyse and accelerate future studies. This is a worthy perspective for future research powered by technology.

Conclusion

Furthering research on dementia through collaborative partnerships

Over time, technology has played two roles in furthering research on dementia across Europe.

With Europe's priority in dementia research by technology, there will be more opportunities to see high-quality research studies done with researchers, experts, communities, stakeholders and governments across different countries working together. As a result, the interconnectivity of local municipalities on dementia might be strengthened.

Similarly, there will be better ways to collate and analyse data. This would result in better research outcomes that can contribute to the development of timely and early psychosocial interventions. Researchers are more capable to uncover gaps in addressing the complex issues of dementia condition and caregiving through new research concepts and methods enabled by technology.

Sources:

Bottanelli, F., Cadot, B., Campelo, F., Curran, S., Davidson, P., Dey, G., Raote, I., Straube, A. & Swaffer, M. (2020). Science during lockdown – from virtual seminars to sustainable online communities. *Journal of Cell Science*, 133. doi: 10.1242/jcs.249607.

Egan, K. J., Pinto, A., Bighelli, I., Berg-Weger, M., van Straten, A., Albanese, E., Pot, A-M. (2018). Online training and support programs designed to improve mental health and reduce burden among caregivers of people with dementia: a systematic review. *Journal of the American Medical Directors Association*, 19(3), s. 200–206.e1. doi: 10.1016/j.jamda.2017.10.023.

Martin, A., O'Connor, S. & Jackson, C. (2018). A scoping review of gaps and priorities in dementia care in Europe. *Dementia*, 19(7), 2135-2151. doi: 10.1177/1471301218816250.

Williamson, T. (2016). Mapping dementia-friendly communities across Europe. *European Foundations' Initiative on Dementia*. Retrieved on January 21, 2021, from https://ec.europa.eu/eip/ageing/sites/eipaha/files/results_attachments/mapping_dfcs_across_europe_final.pdf.