

INTERDEM network celebrates 20 years

Myrra Vernooij-Dassen, INTERDEM Chair, Esme Moniz-Cook, Co-chair and Rabih Chattat, Board member highlight some of the network's key achievements of the past 20 years.

INTERDEM, is a pan-European network of clinical and social care academics with a research focus on the psychosocial care of people with dementia and those that support them. Over its near 21 year history it has successfully brought together dementia care researchers from across Europe to share, collaborate in new research and to disseminate findings. In this way INTERDEM contributes to placing the psychosocial needs of people with dementia and their relatives, on the European research agenda.

At the turn of the century there was a growing number of people with dementia, and policy makers were becoming increasingly aware about the impact of the condition. At

the time, there was just one drug thought to help in a small way, and little knowledge about how to support people with dementia and their families. Worldwide there was a huge gap to fill. Following a preliminary investigation "Early Detection and Psychosocial Rehabilitation to Maintain Quality of Life in Dementia", the multi-professional pan-European network of dementia

researchers INTERDEM (Early detection and timely INTERvention in DEMentia) was founded in Hull, United Kingdom (1999). Our aim was to guide research and related practice activities, with a mission to develop and disseminate early, timely and quality psychosocial interventions in order to enhance practice and policy. We also aspired to place people with dementia and their supporters at the centre of European research.

Strategy

How did the initiative work? Meeting to develop ideas and to collaborate was considered to be crucial. The first steps were taken in the year 2000 where the Fundacion INTRAS (Spain) brought its creativity and generosity, through organising a meeting and hosting of the INTERDEM website to allow communication and activities to begin.

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INTERDEM Annual Meeting, 23 October 2019, The Hague

Soon, we achieved funding from the EU, for two small projects. These allowed us to have further meetings, to grow capacity across Europe, and to develop larger collaborative projects. We embarked on a project collaboration (EuroCoDe) with Alzheimer Europe and started joining their annual meetings. A more formal organisation was set up, with a small board, and a structured yearly members' meeting, at which new initiatives were developed. To engage in the European grant competition, INTERDEM organised meetings to write collaboratively. These efforts have reaped rewards, in the form of joint projects, and publishing of high quality collaborative articles, as well as special issues with position papers on special topics. For example we have published two Manifestos to guide psychosocial dementia research; two books on translating research on timely interventions into practice; and numerous intervention articles.

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Timely interventions

The focus was on developing psychosocial interventions to be used in health and social care practice. These covered a wide range of topics, including: the experience of living with/adjusting to/coping with a dementia for both the person with dementia and carers; the organisation of care services; and training / education for those providing care. Particular attention was given to specific intervention approaches, such as: for “behaviour that challenges”; cognitive stimulation; and occupational therapy. Currently

technology, community environmental interventions, social health, intercultural aspects of interventions, and prevention, are areas of special interest, each with a dedicated taskforce assigned to it.

Methodology is key in scientific research. INTERDEM took a critical stand towards prevailing methods such as the randomised controlled trial, by exploring the value of qualitative approaches and promoting the use of implementation science, which pays special attention to the context of interventions thus avoiding the failure of promising interventions. We contributed to this methodological debate with a focussed taskforce and articles such as “Raising the standard of applied dementia care research” and consensus papers on outcomes measures.

European perspective and education

The European perspective has always been prominent. The majority of the 220 members of INTERDEM are from the most active countries in European dementia research. 23 countries are represented (19 EU countries) in our membership, demonstrating a dominant pan-European perspective. INTERDEM has a memorandum of Understanding (MoU) with Alzheimer Europe – a partnership which strengthens both the European and the Patient and Public Involvement (PPI) perspective, with key joint articles on PPI and outcome measurement. Our pan-European grants and the connections between members and European organisations such as the EU Joint Programme – Neurodegenerative Disease Research (JPND), The European Alzheimer Disease Consortium (EADC), and the European Association of Geriatric Psychiatry, further strengthen our European-focussed infrastructure.

Ensuring dementia researchers have the tools they need to move forward successfully is of

paramount importance for the future of the field. This may be achieved through teams where junior researchers collaborate with and are mentored by senior research teams. In order to prepare the next generation for dementia research, the INTERDEM Academy is a new and vibrant initiative.

The focus, so far, has been on the effectiveness of interventions rather than on the mechanisms by which these may work. Psychosocial interventions could be improved by considering the underlying mechanisms of change including those associated with dementia pathology. Given the huge impact of dementia worldwide, and the absence, to date, of a significant breakthrough in curative solutions, a way forward may be to seek better understanding of the interaction between biomedical and psychosocial paradigms. A hypothesis about the influence of social health on cognitive reserve could guide new interventions.

Over the past 20 years, INTERDEM has become a platform for the exchange of new knowledge and for building collaborations and careers. Its driving force is the engagement of European researchers in a network that has become greater than the sum of its parts – that is, INTERDEM inspires its members and receives inspiration in return.

The INTERDEM network, at the European level, plays an important role in disseminating new knowledge, stimulating and informing researchers and policy makers about new evidence-based interventions for the care of people with dementia, their relatives and care organisations. Through Alzheimer Europe, we also engage with the members of the European Working Group of People with Dementia (EWGPWD), who are positive in their review of our dissemination activities.

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Reflections on 20 years of INTERDEM



Esme Moniz-Cook, INTERDEM Co-chair

I discovered through case studies that interactions for some people with dementia are shaped by their beliefs traditions and cultures – and that others (carers) might misunderstand the role of these (unconscious) beliefs by ascribing behaviour to the dementia rather than to the needs of the person. Europe provides – like no other– a rich tapestry of cultures, traditions and languages from which we may learn from each other on how to overcome some of the societal challenges associated with dementia. An early understanding of each person and family to prevent the challenges of this condition through timely knowledge and support, has been the hallmark of what I had hoped for at the inception of INTERDEM in 1999. Now we need to recover from the continued societal fear of dementia. People with dementia across Europe have, I believe, a strong contribution to make to future psychosocial research, if we are to understand how they – living in their environments – might improve knowledge on reducing or overcoming the disabilities associated with dementia.



Rabih Chattat, INTERDEM Board member

The future challenge and hope for INTERDEM will be: connecting psychosocial and biomedical research and recognising common ground; enhancing the partnership and the collaboration between researchers and people with dementia; and the implementation of research results across European countries.



Jean Georges, Executive Director, Alzheimer Europe

Big congratulations are due to the INTERDEM leadership and the whole team for their achievements over the past twenty years. Alzheimer Europe has been lucky to have been closely associated with this fantastic network of researchers from the early beginnings and our joint work on the EuroCoDe project (European Collaboration on Dementia). I am truly impressed how both organisations are working together to improve the lives of people living with dementia, combat stigma, develop meaningful outcomes and promote a holistic approach to dementia research. Together, we are undoubtedly stronger and I look forward to our continued collaboration.



Myrra Vernooij-Dassen, INTERDEM Chair

I am most proud, over the past 20 years of INTERDEM, of: development of effective interventions to support people living with dementia; addressing new potential for interventions including social health; stimulating interdisciplinary research; addressing methodological problems in intervention research; the dedication and growth of the INTERDEM network; and the INTERDEM Academy for young researchers.