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## Bridging the divide between biomedical and psychosocial approaches in dementia research: the 2019 INTERDEM manifesto

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### ABSTRACT

**Objective:** To provide a new perspective on integrated biomedical and psychosocial dementia research.

**Background:** Dementia is being recognized as a multifactorial syndrome, but there is little interaction between biomedical and psychosocial approaches. A way to improve scientific knowledge is to seek better understanding of the mechanisms underlying the interaction between biomedical and psychosocial paradigms. One rationale for integrating biomedical and psychosocial research is the discordance between neuropathology and cognitive functioning. The concept of social health might bridge the two paradigms. It relates to how social resources influence the dynamic balance between capacities and limitations.

**Hypotheses:** Social health can act as the driver for accessing cognitive reserve, in people with dementia through active facilitation and utilization of social and environmental resources. Thereby we link lifestyle social and opportunities to the brain reserve hypothesis.

**Manifesto:** We provide a Manifesto on how to significantly move forward the dementia research agenda.

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Dementia and cognitive disorders; psychological and social aspects; social support; psychosocial interventions; cognitive functioning

## Background

Dementia has physical, psychological, social, and economic consequences for people with dementia, their carers, families, and society at large (World Health Organisation, 2017). In Europe 10 million people had dementia in 2010 and this number is expected to rise to 19 million by 2050 (Prince et al., 2013).

Despite dementia being recognized as a multifactorial syndrome (Winblad et al., 2016), research to date appears to have developed with little interaction or cross-fertilization between biomedical and psychosocial approaches, each overlooking potential influential factors from the other to the detriment of both paradigms. This perspective article contributes to the dementia debate by outlining an in-depth perspective on interdisciplinary dementia research.

Biomedical research has undoubtedly led to better understanding of the ageing brain. It has focused on the search for a curative treatment for dementia, but despite huge efforts this is proving challenging (Winblad et al., 2016). Psychosocial research has had some success in the development of effective interventions and improvements in care practice. It has also made progress in considering how people with dementia, carers and the public can themselves guide new research (Gove et al., 2018). The

focus, vision and ambition of psychosocial dementia research, has been strongly influenced by the European INTERDEM (Early detection and timely INTERvention in DEMentia) network ([www.interdem.org](http://www.interdem.org)) and its initial 2011 Manifesto (Moniz-Cook, Vernooij-Dassen, Woods, & Orrell, 2011). INTERDEM is a pan-European network of dementia researchers aiming at improving the quality of life of people with dementia and their supporters across Europe. However, little research has been conducted to inform the underlying mechanisms of changes associated with dementia pathology and there is an underinvestment in the role of social factors in dementia research. Given the huge impact of dementia worldwide, and the absence to date of a significant breakthrough in curative research, a way forward may be to seek better understanding the interaction between biomedical and psychosocial paradigms.

The rationale for integrating biomedical and psychosocial research is the discordance between neuropathology and cognitive functioning (Winblad et al., 2016). This means that although the role of biomarkers is significant, they do not account for all clinical and epidemiological aspects of disease onset and progression. Epidemiological data revealed that clinical features of the disease are also influenced by other factors, including social factors, which

modulate disease onset and progression (Hersi et al., 2017; Livingston et al., 2017)

We explore new ideas for the pathogenesis of AD through connecting biomedical and psychosocial approaches. We also examine new avenues on how people with dementia and their families can live as well as they can, irrespective of dementia pathology. This can also contribute to prevention of disability and dementia.

The aim is to provide a new perspective on integrated biomedical and psychosocial dementia research. First, we examine the strengths and limitations of biomedical and psychosocial approaches to date. Next, we consider the rationale for integration of relevant aspects of the two paradigms. We consider hypotheses-led research related to the underlying interaction between biomedical and psychosocial concepts such as cognitive reserve and social health. We conclude with a call for action in a new manifesto and a refreshed research agenda for dementia research over the next five years.

INTERDEM (Early detection and timely INTERvention in DEMentia) [www.interdem.org](http://www.interdem.org)) is a European organisation of psychosocial dementia researchers. It has more than 200 members including psychologists, medical doctors, nurses, sociologists and health scientists. Activities include joint research and articles, special issues on social health and person-centred care and taskforces on methodology, social health, technology and prevention. INTERDEM takes responsibility in addressing key research issues related to dementia, such as outcomes, personalized care and multidisciplinary research. There is a strong connection with Alzheimer Europe and the Patient and Public Involvement. INTERDEM has initiated an Academy to help develop and train early-career researchers to carry out high-quality research in this field. The INTERDEM Academy gives access to a comprehensive research training program that deepens the understanding of the nature of dementia and trains young researchers in methodological excellence, creative innovation and intellectual leadership.

### Strengths and limitations of biomedical approaches

For most of the twentieth century, Alzheimer's disease was considered as a pre-senile dementia, affecting people aged below 65 years. In this way, it was conceptualized as distinct from senile dementia, which was viewed to be the result of ageing. The identification of post-mortem brain pathology in people with senile dementia in the late 1960s (Blessed, Tomlinson, & Roth, 1968), led to redefinition of dementia occurring at any age as Alzheimer's disease and the framing as a true brain disease (Katzman, 1976). Conceptualizing dementia as a brain disease rather than a consequence of ageing has engendered a political agenda with enormous global consequences, for science and society, powerfully driving research, awareness and social attitudes. While ageing calls for acceptance and a supportive approach, a disease calls for active interventions, which can potentially be curative. The expectation that neurobiological research would lead to a rational treatment resulted in an exponential growth of this branch of science, applied to neurodegeneration. A strength of this approach is that progress in biomedical research has led to a better understanding of the ageing brain and a diversity of theories about ageing and dementia. However, a consequence of the dominance of the neurobiological approach is a potential disconnect from the lived experience of the condition. Recent research criteria of the National Institute on Aging

and Alzheimer's Association (NIA-AA) propose that a diagnosis of Alzheimer's disease is made on the basis of evidence of neuronal atrophy or injury and biomarkers (Jack et al., 2018), even in people who lack any signs or symptoms of cognitive deterioration. This has led to the notion of asymptomatic Alzheimer's disease. The authors acknowledge that diagnostic biomarker criteria are recommended for research purposes and are not yet 'ready' for clinical diagnostics.

However, the attention on deficits rather than capacities, especially in public campaigns, has increased the sense of hopelessness associated with dementia. Accordingly, dementia has now replaced cancer as the most feared health condition for people over the age of 50 (Department of Health England, 2013). More disturbingly, no effective treatment is available today, and there is little outlook of one (Drachman, 2014; Selkoe, 2019). Therefore, redefinition of Alzheimer's disease and new avenues to better deal with the dementia syndrome are needed. A major limitation of this pathology-led approach to Alzheimer's disease is that it overlooks the potential of brain resilience and ignores two major problems associated with a classic disease model (Richards & Brayne, 2010). Firstly, there is no consistent relationship between the clinical features and many of the neurobiological hallmarks of Alzheimer's disease, and plaques and tangles are not pathognomonic. Nearly 50% of very old people with dementia did not have sufficient brain neuropathology to explain their cognitive symptom (Balasubramanian, Kawas, Peltz, Brookmeyer, & Corrada, 2012). Another striking finding is that high levels of AD pathology were present in one third of very old people without dementia (Corrada, Berlau, & Kawas, 2012). Secondly, in these age groups, pathology is far more heterogeneous than previously believed, with a mixture of plaques and tangles and cerebrovascular disease, even in patients who are clinically diagnosed with probable Alzheimer's disease (Richards & Brayne, 2010).

There seems to be emerging epidemiological consensus that lifestyle factors are important avenues of prevention, and are therefore relevant to treatment (Fratiglioni, Paillard-Borg, & Winblad, 2004; Kuiper et al., 2015; Salinas et al., 2017). This provides common ground for prevention interventions and new perspectives to influence the course of dementia.

Instead of focusing primarily on biomarkers and brain imaging, it is time to apply a more comprehensive model of dementia, encompassing the relationship between the variety of biological, psychological and social factors.

### Strengths and limitations of psychosocial approaches

#### Psychosocial interventions

Since the publication of the first INTERDEM manifesto (Moniz-Cook et al., 2011), there has been considerable progress in the development and rigorous evaluation of psychosocial interventions in dementia.

Most psychosocial interventions in dementia are at a micro-level, relating to small-scale interactions between individuals. The strength of these interventions is that they can reduce excess disability and stimulate the person with dementia to make to most of their underlying capabilities,

including cognitive functioning, skills and function, to compensate for limitations and assist with mood and emotion regulation. These approaches do not have harmful side effects and several approaches have been proved to be effective. Multi-component exercise and cognitive stimulation as well as functional analysis-based interventions have worthwhile benefits for people with dementia related to cognition, behavior, daily functioning and quality of life (McDermott et al., 2018). Psychosocial approaches are, together with pharmacological options, now part of mainstream dementia care. Palliative care interventions in dementia focus on person-centered support, and living and dying well with dementia (The Lancet, 2018). Recent examples of effective interventions include educational training in nursing homes and in general practice (Smets et al., 2018; Tilburgs et al., 2018).

Moreover, psychosocial interventions used the potential of assistive technology and showed that technology offers promising ways to tailor accessibility, personalization and sustainability of interventions from prevention to palliative care (Meiland et al., 2017). Cost-effectiveness of psychosocial interventions is strongly influenced by their potential to improve quality of life and to reduce costly hospital or care home admissions. Specialist personalized, multicomponent psychological support to family carers, have been shown to reduce the frequency of care home admissions (Livingston et al., 2017). Projects facilitated by INTERDEM have examined cross-national implementation of cost-effective interventions such as meeting centers (Brooker et al., 2018).

Psychosocial interventions can also support family carers affected by dementia (World Health Organisation, 2012). Multicomponent interventions including personal carer focused interventions can reduce depressive symptoms and improve quality of life in carers, reduce carer burden, and reduce behavioral and psychological symptoms of dementia as well as carer upset with these symptoms (Laver, Milte, Dyer, & Crotty, 2017).

The wealth of initiatives is promising. Evaluation reveals the value of person-centered and multi-component approaches, the consideration of the societal context and the attention for carers. These approaches should be preserved and enhanced. Effective approaches should be implemented systematically.

However, there are limitations that require mitigation. Not all interventions have proven effective, and it is often difficult to implement interventions widely.

The use of technologies evoked concerns about the reliability of the technology and acceptability by users and professionals (Meiland et al., 2017). New paradigms for evaluating effectiveness are required, with the Internet and technologies moving on too quickly to afford the luxury of a randomized controlled trial lasting several years. Thus, Van der Roest, Wenborn, Pastink, Droes, and Orrell (2017) were unable to identify any RCTs of assistive technology for supporting memory in people with dementia.

Whilst some interventions have significant effects, in absolute terms the effects may be relatively small for a given individual, in comparison with the scale of changes being experienced. A robust finding is that more personalized interventions are most effective, with evidence that 'one size does not fit all' (Brodaty, Green, & Koschera, 2003;

Kim & Park, 2017; Van Mierlo, Van der Roest, Meiland, & Droes, 2010). Research to date has often not been informative enough about who will benefit most from a specific intervention. The challenge comes from identifying what will be helpful for a particular individual living with dementia, rather than the effects on the average person. To move forward in dementia research, better methodology using theoretical models may enhance knowledge on why and how interventions work or fail in relation to dementia (Vernooij-Dassen & Moniz-Cook, 2014). It also requires a shift in methodology to collect evidence in a more personalized way with sensitivity to context, biomedical information and individual goals. Goal setting approaches are an example of how this could be practically achieved (Clare et al., 2019). Adaptations at this personalized level are in line with the personalized medicine agenda. A key barrier to current psychosocial dementia research is the lack of integration with biological models. Finally, in the psychosocial field, effective approaches are implemented sporadically at best, and differences in culture, language and care systems between and within countries mean that transferring findings from one context to another requires careful planning and evaluation (Aguirre, Spector, & Orrell, 2014; Spector et al., 2019).

The current interventions aim at restoring 'lost capacities'. New perspectives for psychosocial interventions shift the focus to 'remaining capacities'. These perspectives include better use of public and patient involvement (PPI), more attention for the potential of social health and more attention for dementia pathology by better integration with biomedical research. These are all fields in development. In the following sections, we explain more on their potential.

### **Public and patient involvement**

Public and patient involvement provides an avenue for people with dementia to confirm their place in society. The negative framing of dementia in public discourse as a scourge, dread disease, avalanche, apocalypse, plague, epidemic, or living death is challenged by the growing international, national and local communities of people living with dementia who self-advocate. They take their place in the dementia debate, asserting: 'Nothing about us without us'. Psychosocial research has embraced the development of this movement, often working with Alzheimer organizations such as Alzheimer Europe and national Alzheimer societies. Accordingly, INTERDEM has a Memorandum of Understanding with Alzheimer Europe confirming the collaboration with regards to PPI. Alzheimer Europe's position statement on PPI in research outlines the potential for wide-ranging activities for people with dementia and those that support them, such as acting as consultants, identifying research topic priorities, contributing to ethical debates, interpretation of findings and dissemination (Gove et al., 2018). The research agenda has already benefited from the involvement of people with dementia and their supporters, especially in the UK (Bethell et al., 2018; Miah et al., 2019).

New initiatives in the psychosocial arena aim to engage the public and wider society in dealing with dementia in daily life and to change the negative framing and stigma. They acknowledge the right to live well with dementia and



relate to 'normal life'. On the meso-level of communities and organizations training interventions are seen for staff working in a variety of organizations, such as banks, supermarkets, transport providers and police; and art galleries and cinemas have 'dementia friendly' events. Neighborhood and Civil initiatives (Dementia Friends) are in place including Dementia friendly communities (Alzheimer Europe, 2015). These initiatives have out-paced related research, but projects are now commencing e.g. the Social citizenship UK project (Ward et al., 2018). On a macro-level new initiatives include television commercials on how to deal with people with dementia, and governmental campaigns to focus attention on dignity (Dutch Ministry of Health, 2015). Around the world 81% of countries participating in the WHO Global Dementia Observatory initiative have a dementia awareness campaign (The Lancet, 2017). There are numerous novels, plays, films and even operas in which dementia is depicted as a central theme, with dementia now receiving almost as much attention in arts and culture as in the health and care sector.

### Social health

In dementia, people more than ever require to depend on other persons, not only for practical support, but also to find a balance between their capacities and limitations. However, there is an underinvestment in studying the role of social influences, even within psychosocial interventions. There is a need for an overarching lens through which studies of social influences on dementia can be brought into focus (Vernooij-Dassen & Jeon, 2016). The concept of social health provides an umbrella to study how social resources influence the dynamic balance between capacities and limitations. The dimensions of social health include the capacity to fulfill potential and obligations, to manage life with some degree of independence and to participate in social activities (Huber et al., 2011). Applying the social health concept to dementia research allows improved understanding of how people, their social networks and wider society with its norms, interact with the condition. For example, more time spent with others and better communication were associated with better ADL functioning across all dementia severity (Budgett et al., 2019). An important new finding is that sensitivity to others did not differ between dementia severity levels and was a preserved domain throughout dementia (Budgett et al., 2019). This potential facilitates fulfilling social obligations and interventions can draw on these retained resources. On a biological level, greater emotional support was found to be associated with higher brain-derived neurotrophic factor (BDNF). BDNF is a neuroprotective molecule, critical for synaptic plasticity and neuronal repair (Salinas et al., 2017).

Social health connects both to normalcy and to neuropathology (Vernooij-Dassen & Jeon, 2016). Moreover, the introduction of the concept of social health in dementia research provides a recognizable label for communication and synergy scientific paradigms in dementia research.

INTERDEM has championed social health in dementia research, bringing together two special issues in relevant journals on this topic. This has harnessed a growing research agenda (de Vugt & Dröes, 2017) and includes a

consensus-based inventory of concepts under the umbrella of social health, from the work of the INTERDEM taskforce on Social Health (Dröes et al., 2017). The social experiences of people with dementia and the dynamics within social networks are now being described (Vernooij-Dassen, Moniz-Cook, & Jeon, 2018). For example, an investigation of lived experiences revealed that people with dementia can feel they are being treated as an 'other' rather than 'one of us', and as 'lesser' rather than a full, valued member of society (Patterson, Clarke, Wolverson, & Moniz-Cook, 2018). Fear of being unable to communicate according to accepted norms and the shame of revealing deterioration has been shown to prevent people with dementia from engaging in social contacts (Donkers et al., 2018).

These examples of social health studies in dementia show its huge potential in the understanding of modifiable factors associated with the onset and course of dementia.

### Bridging biomedical and psychosocial research in dementia

Biomedical and psychosocial approaches continue to develop separately from each other. Although each has developed into fruitful disciplines, there is the danger of inconsistency and tunnel vision. The focus of this current manifesto is to propose that the *zeitgeist* of dementia research moves to a more integrative bio-psychosocial approach, since this does greater justice to phenomenology and pathology of people living with dementia. The strength of the separate approaches provide the clues for an integrative approach by indicating a range of protective and compensatory factors. Certain compensatory factors (e.g. high education, social engagement, maintenance of cardiovascular health and mentally stimulating activities) enhance cognitive and brain reserve. Emerging epidemiological evidence suggests that higher levels of social participation reduce occurrence and progression of cognitive impairment and dementia (Fratiglioni et al., 2004; Kuiper et al., 2015; Salinas et al., 2017). Social health factors can influence brain structure (Kwak, Joo, Youm, & Chey, 2018) and may contribute to brain reserve and enhance the plasticity of the brain (Fratiglioni & Wang, 2007). The brain reserve hypothesis refers to the capacity of the brain to resist the impact of brain pathology through plasticity that uses pre-existing cognitive processes or by activating compensatory approaches (Fratiglioni & Wang, 2007; Qiu & Fratiglioni, 2018). This opens avenues for influencing the onset, and the course of dementia.

A framework to study the integration of biomedical and psychosocial factors is positive health. Applying the framework of positive health to dementia allows a focus on both capacities and deficits and on the ability to adapt and self-manage by connecting the three constituent domains: physical, mental and social health (Huber et al., 2011). We hypothesize that social health can act as the driver for accessing cognitive reserve in people with dementia, through active facilitation and utilization of social and environmental resources. Herewith we relate to the brain hypothesis (Fratiglioni & Wang, 2007). Social interactions may trigger reactions, which might require the use of pre-existing cognitive processes or activating compensatory approaches (Fratiglioni & Wang, 2007).

Our hypothesis will guide two new ambitious interdisciplinary dementia studies: the study on the influence of social health on the onset of dementia (Kas et al., 2018) and on the course of dementia (Ikram et al., 2019). The hypothesis might also stimulate current clinical practice and civic interaction by focusing on assets or capacities rather than limiting work to deficit or needs-based models. This may stimulate social inclusion and prevent social withdrawal.

Often, new insights are incremental involving small steps: in this case hypothesis-led integration of biomedical and psychosocial research and the inclusion of underexplored paradigms such as social health. Good examples of this unified approach are to be found in epidemiological work on risk factors for dementia, where we see genetic risk factors having an influence alongside biomedical aspects, such as hypertension, in combination with psychosocial influences, such as smaller social networks (Livingston et al., 2017). The unified approach may also help to underpin new personalized diagnostic and therapeutic strategies and reveal opportunities for more effective interventions through interruption of the vicious cycle of 'malignant social psychology' cycle which Kitwood (1997) argued could be linked to neurological impairment.

Call to Action: the 2019 INTERDEM Manifesto. To significantly move forward the dementia research agenda in the next five years we call for:

1. *Work on approaches and concepts at the interface of biomedical and psychosocial approaches*, thus all potential domains are utilized fully – social, psychological and physical. This will need recognition of common ground, developing better communication and understanding of the contributions from different fields. Bridging this gap has the potential for progressing knowledge on preventing and delaying the dementias.
2. *Recognition of social health as a specific area for development*. This has huge potential for informing new interventions that may prevent or delay the onset of dementia. Both psychosocial and biomedical approaches need to be engaged across the spectrum of the conditions and severity, from prevention to palliative care, where physical health, pain and co-morbid health conditions are major influences on quality of life and well-being.
3. *Development of models of co-production in dementia research*. The research agenda has already benefited from the involvement of people with dementia and their supporters, but further progress towards partnership and co-production is needed. Some areas of research such as advanced dementia and palliative care may require new models of involvement and engagement.
4. *Harnessing the power of new technology to the benefit of people with dementia*. New technology may be effective for prevention, making the diagnosis, and helping people with dementia with the physical, psychological and social consequences of the disease. It offers ways to tailor accessibility, personalization and sustainability of interventions from prevention to palliative care. As new cohorts of people develop dementia, with

greater familiarity with technology, the potential will grow further, and a balance must be sought between bespoke solutions (including care robots) and the widespread use of ubiquitous technologies (such as smart phones). From a research perspective, new paradigms for evaluating effectiveness are required.

5. *Interventions to be individualized*. This is an area of common ground for psychosocial and biomedical paradigms offering the opportunity to develop personalized approaches to evaluation and recognizing that targets for health and social care will not be the same for different individuals. Methods of outcome assessment could be coordinated across biomedical and psychosocial approaches. Goal setting approaches are an example of how this could be practically achieved. If the mechanisms of change for individual cases can be understood more fully, then there is the scope for making progress in relation to what works for whom, when and where.
6. *Greater attention to implementation of research findings*. In the psychosocial field, effective approaches are implemented sporadically at best, and differences in culture, language and care systems between and within countries mean that transferring findings from one context to another requires careful planning and evaluation. Care research needs to be related to National Dementia Plans, and country specific priorities such as coordination of care in countries with many care facilities and access to treatment in countries with poor facilities must be addressed. The input of people living with dementia and carers will be essential here also.

## Disclosure statement

No conflict of interest stated by the authors.

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