

## GUEST EDITORIAL

# Social health and dementia: the power of human capabilities

No breakthrough has been made in dementia research to find a cure in the last century (Selkoe, 2012), but a great deal of progress has been made in the description of pathology. The damage caused by this multifaceted “disease” has been described in terms of its physical, neuropsychological, and social manifestations at an individual level but also its societal impact at large, often in financial terms.

Of course, we need to understand pathology and negative consequences of the disease. Without such understanding, no direction of what to cure or to compensate is possible. Yet, this current focus on what Oliver Sacks calls “defectology” (Sacks, 1985) neglects the remaining capacity of the person with dementia and the possibilities to compensate for the deficits. The remaining capacity can be addressed by the concept of social health. Social health involves making a dynamic balance between opportunities and limitations, affected by external conditions such as social and environmental challenges. Several dimensions can be identified including people’s capacity to fulfill their potential and obligations, the ability to manage their life with some degree of independence despite a medical condition, and the ability to participate in social activities including work (Huber *et al.*, 2011).

The aim of this guest editorial is to provide an analysis of the concept of social health and to highlight its potential to contribute to living well with and without dementia.

The concept of social health addresses the gap inherent in the WHO definition of health, being “a state of complete physical, mental, and social well-being”. The gap between complete health and the health status of most people with chronic/long-term conditions is that they will not be able to achieve complete well-being. Social health in this regard acknowledges that the person does not have to strike a perfect (complete) chord to reach the status of well-being. Instead, the state of well-being can be achieved as they are able to make adaptations to their limitations and seize opportunities to reclaim some of their abilities, while maintaining a balance between the ability and the disability, in the context of their social, psychological, and physical environments (Huber *et al.*, 2011). Not acknowledging the individual’s potential can create an additional threat to their capacity to lead a quality life, as powerfully described by an international

advocate for dementia at the First WHO Ministerial Conference on Global Action Against Dementia in 2015.

When I was diagnosed with dementia at the age of 49, I was told to get my end of life affairs in order, to give up work, to get acquainted with aged care, and to go home for the time I had left. I term this Prescribed Disengagement, but chose to ignore it and with support from the disability sector, engaged in authentic brain injury rehabilitation and other non-pharmacological and positive psychosocial interventions for dementia, including advocacy (Swaffer, 2015).

People with dementia not only have to deal with their brain problems but also are further threatened by such “prescribed disengagement” (Swaffer, 2015).

## Social health and dementia research

In dementia research, despite a heavy investment on a biomedical focus, the most promising results have come from epidemiological research, “borrowing” potential risk and protective factors for dementia from cardiovascular research. It has been found that mental, physical, and social factors equally contributed to decrease dementia risk (Karp *et al.*, 2006). For example, there is a strong connection between dementia and poor social engagement, comparable with other well-established risk factors for dementia, including physical inactivity and low education (Bennett *et al.*, 2006, Kuiper *et al.*, 2015). Social pathology is also an important part of dementia diagnostics: the changes in social behavior is one of the most recognizable symptoms of dementia and very burdensome for the family caregivers (Moniz Cook *et al.*, 2012; Haro *et al.*, 2014).

An accumulation of three decades of psychosocial research on dementia care has revealed the power of social engagement, environmental support, and remaining capabilities of the person with dementia. Such development in our understanding of social health challenges the common belief that dementia cannot be prevented and that capabilities of people with dementia cannot be maintained or be improved.

We argue that social health provides an overarching lens through which our endeavors to better health and well-being of people with dementia can be brought into focus, for example, restorative care or reablement (Galik *et al.*, 2014), individually tailored activities and environmental modifications (Graff *et al.*, 2006; Gitlin *et al.*, 2008, Gitlin *et al.*, 2010) and person-centered care (Edvardsson *et al.*, 2008). Social health is an umbrella term that embraces an array of concepts reflecting human capacities to participate in social life such as reciprocity and dignity (Vernooij-Dassen *et al.*, 2011), and resilience (Gaugler *et al.*, 2007). More importantly, seeing the person with dementia from the perspective of social health, inescapably leads us to focus on the person's needs (love, comfort, attachment, involvement, identity, and meaningful occupation) and their positive and negative experiences (Kitwood, 1997).

Thereby, social health goes beyond pathology and relates to normalcy and positiveness, and to wider society including its norms dealing with mental illnesses. Researchers around the globe have made a remarkable progress in demonstrating the importance of emphasis on social health in dementia care and preventing and reducing disengagement.

For example, the Care of Persons with Dementia in their Environments (COPE) program aimed to reduce environmental stressors affecting the capabilities of the person with dementia in their home, while optimizing their capabilities through engaging them in their physical health, daily activities, and supporting caregivers. The COPE program was delivered by occupational therapists and an advanced practice nurse over four months, involving a comprehensive set of assessments (physical, medical, social, relational, and environmental aspects), caregiver education, and training. At four months ( $n = 107$  dyads in the control and 102 dyads in the intervention group), COPE improved the person's instrumental activities of daily living (telephone, shopping, meal preparation, housework, laundry, travel, medicine, managing finances) and their engagement in activities, and caregiver well-being and confidence using activities (Gitlin *et al.*, 2010). Similarly, underpinned by person-centered care principles and the Social Ecological Model, Function-Focused Care (FFC) targeting supporting residents with cognitive impairment in nursing homes, aims to shape and work on the goals aligning with their preferences and capabilities. While addressing intrapersonal, interpersonal, environmental, and policy factors that can affect their well-being, FFC significantly improved the amount and intensity of physical activity and physical function at six months (Galik *et al.*, 2014). These programs have acknowledged the person's desires and capabilities

to fulfill their independence and engage in everyday activities including social. A Danish Alzheimer Intervention Study (DAISY) of a multifaceted intervention, designed to optimize capabilities of the person with dementia including semi-tailored counseling, education and support, also demonstrated positive outcomes in depression scores for people with dementia and in quality of life of their caregivers (Waldorff *et al.*, 2012). The semi-tailored design of the DAISY was a distinctive feature of the program as it involved a combination of individualized and structured approaches to care. Furthermore, new initiatives to prevent and reduce disengagement are taken on a societal level such as dementia-friendly communities try to stimulate social participation for instance by educating and training staff working in supermarkets and banks (Alzheimer's Disease International, 2012).

The results of those interventions focusing on social health are gradually contributing to a turning point in dementia care and policy: the replacement of the disaster scenario with the scenario of living well with dementia. Yet, more needs to be done for a breakthrough in dementia care. Social health should be included in models on causes of dementia as well as in models to reduce its consequences. Social health aspects may contribute to brain reserve and might also be crucial in optimally using the plasticity of the brain (Valenzuela and Sachdev, 2006; Fratiglioni and Wang, 2007). This can be done through active facilitation and utilization of social and environmental resources individuals possess.

Despite growing evidence of the importance of the concept of social health for prevention and management of dementia, which is directly applicable in clinical care and daily life of the person with dementia and their carers, social health is still an underestimated opportunity in the medical community. This paper will help medical readers raise awareness of the importance of social health in dementia and hopefully offer them an avenue to different approaches to their practice: looking beyond a bio-medical model of health.

Social health is a recognizable label that helps researchers, practitioners, and policy-makers communicate with others scientific levels in dementia research. Parallel to efforts to improve adolescent mental health (Lee *et al.*, 2014), we advocate for new avenues in dementia research that bridge discoveries in biomedical and social sciences and use the potential of social health to guide novel interventions. We propose social health serves as a new paradigm in dementia research.

### Conflict of interest

None.

## Acknowledgments

We thank Professor Gert Westert, Radboud University Medical Centre Nijmegen, Professor Frans Verhey, psychiatrist, of the Maastricht University Medical Center, Professor Esme Moniz-Cook, psychologist, of the University of Hull, and Professor Robert T. Woods, psychologist, of Bangor University for reviewing this manuscript and their feedback.

MYRRA VERNOOIJ-DASSEN<sup>1</sup> AND YUN-HEE JEON<sup>2</sup>

<sup>1</sup>Scientific Institute for Quality of Healthcare, Radboud University Medical Centre, Nijmegen, The Netherlands

<sup>2</sup>Sydney Nursing School, University of Sydney, Camperdown, Australia

Email: [Myrra.Vernooij-Dassen@radboudumc.nl](mailto:Myrra.Vernooij-Dassen@radboudumc.nl)

## References

- Alzheimer's Disease International** (2012). *World Alzheimer Report 2012: Overcoming the stigma of dementia*. London: Alzheimer's Disease International.
- Bennett, D. A., Schneider, J. A., Tang, Y., Arnold, S. E. and Wilson, R. S.** (2006). The effect of social networks on the relation between Alzheimer's disease pathology and level of cognitive function in old people: a longitudinal cohort study. *The Lancet Neurology*, 5, 406–412.
- Edvardsson, D., Winblad, B. and Sandman, P. O.** (2008). Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *The Lancet Neurology*, 7, 362–367.
- Fratiglioni, L. and Wang, H. X.** (2007). Brain reserve hypothesis in dementia. *Journal of Alzheimers Disease*, 12, 11–22.
- Galik, E., Resnick, B., Hammersla, M. and Brightwater, J.** (2014). Optimizing function and physical activity among nursing home residents with dementia: testing the impact of function-focused care. *The Gerontologist*, 54, 930–943.
- Gaugler, J. E., Kane, R. L. and Newcomer, R.** (2007). Resilience and transitions from dementia caregiving. *Journal of Gerontology B Psychological Sciences and Social Sciences*, 62, P38–P44.
- Gitlin, L. N., Winter, L., Burke, J., Chernett, N., Dennis, M. P. and Hauck, W. W.** (2008). Tailored activities to manage neuropsychiatric behaviors in persons with dementia and reduce caregiver burden: a randomized pilot study. *The American Journal of Geriatric Psychiatry*, 16, 229–239.
- Gitlin, L. N., Winter, L., Dennis, M. P., Hodgson, N. and Hauck, W. W.** (2010). A biobehavioral home-based intervention and the well-being of patients with dementia and their caregivers: the COPE randomized trial. *JAMA: Journal of American Medical Association*, 304, 983–991.
- Graff, M. J., Vernooij-Dassen, M. J., Thijssen, M., Dekker, J., Hoefnagels, W. H. and Rikkert, M. G.** (2006). Community based occupational therapy for patients with dementia and their care givers: randomised controlled trial. *BMJ: British Medical Journal*, 333, 1196.
- Haro, J. M. et al.** (2014). Analysis of burden in caregivers of people with Alzheimer's disease using self-report and supervision hours. *The Journal of Nutrition Health & Aging*, 18, 677–684.
- Huber, M. et al.** (2011). How should we define health? *BMJ: British Medical Journal*, 343, d4163.
- Karp, A., Paillard-Borg, S., Wang, H. X., Silverstein, M., Winblad, B. and Fratiglioni, L.** (2006). Mental, physical and social components in leisure activities equally contribute to decrease dementia risk. *Dementia and Geriatric Cognitive Disorders*, 21, 65–73.
- Kitwood, T.** (1997). The experience of dementia. *Aging and Mental Health*, 1, 13–22.
- Kuiper, J. S. et al.** (2015). Social relationships and risk of dementia: A systematic review and meta-analysis of longitudinal cohort studies. *Ageing Research Reviews*, 22, 39–57.
- Lee, F. S. et al.** (2014). Mental health. Adolescent mental health—opportunity and obligation. *Science*, 346, 547–549.
- Moniz Cook, E. D., Swift, K., James, I., Malouf, R., De Vugt, M. and Verhey, F.** (2012). Functional analysis-based interventions for challenging behaviour in dementia. *The Cochrane Database of Systematic Reviews*, 2, Cd006929.
- Sacks, O.** (1985). *The Man who Mistook his Wife for a Hat*. New York, NY: Touchstone Books.
- Selkoe, D. J.** (2012). Preventing Alzheimer's disease. *Science*, 337, 1488–1492.
- Swaffer, K.** (2015). Speaker notes: day 2 plenary presentation. *First WHO Ministerial Conference on Global Action Against Dementia*, 17 March 2015, Geneva.
- Valenzuela, M. J. and Sachdev, P.** (2006). Brain reserve and dementia: a systematic review. *Psychological Medicine*, 36, 441–454.
- Vernooij-Dassen, M., Leatherman, S. and Rikkert, M. O.** (2011). Quality of care in frail older people: the fragile balance between receiving and giving. *BMJ: British Medical Journal*, 342, d403.
- Waldorff, F. B. et al.** (2012). Efficacy of psychosocial intervention in patients with mild Alzheimer's disease: the multicentre, rater blinded, randomised Danish Alzheimer intervention study (DAISY). *BMJ: British Medical Journal*, 345, e4693.