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GUEST EDITORIAL

Social health in dementia care: harnessing an applied research agenda

The notion of social health (Huber *et al.*, 2011) as applied to dementia care research was introduced to redress the balance of empirical studies that tended to focus on biomedical, cognitive, and functional status in dementia (Vernooij-Dassen and Jeon, 2016). The introduction of social health has followed the *zeitgeist* of campaigners for a better life for those living with dementia, with initiatives to improve the social images of dementia (Alzheimers.org, 2017). Examples from social research in dementia to examine friendships and the social environments of people with dementia exist (Medeiros *et al.*, 2012), but introduction of the paradigm of social health in dementia (Vernooij-Dassen and Jeon, 2016) has harnessed a growing research agenda (de Vugt and Dröes, 2017). This paradigm provides an umbrella concept to study how social aspects influence the dynamic balance between opportunities and limitations in dementia. Social health goes beyond the neuropathology of dementia, to understand how people, their social networks and wider society with its norms, interact with the condition (Vernooij-Dassen and Jeon, 2016). It is not far removed from the ideas of Tom Kitwood, the pioneer of person-centered dementia care, who noted that "personhood is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being" (Kitwood, 1997). The INTERDEM (Early detection and timely INTERvention in DEMentia, www.interdem.org) psychosocial research agenda aspired to improve knowledge about social inclusion and reciprocal relationships for people with dementia (Moniz-Cook *et al.*, 2011). The concept of social health (Vernooij-Dassen and Jeon, 2016) with its dimensions for dementia research (Dröes *et al.*, 2017) has begun to develop this knowledge-base.

This special issue reflects a collaboration of INTERDEM and PROMOTE (Psychosocial research consortium to advance mental health of older people in the Asian Pacific Region, https://cheba.unsw.edu.au/group/promote) to extend this research agenda with studies on the experiences of people with dementia and social engagement in society, social interactions, social dynamics, and on exploring the potential for broader integration of social health with the neurosciences or other biomedical perspectives.

Social experiences of persons with dementia

The study of Patterson *et al.* (2017) indicates that experiences previously understood as a direct result of dementia might be the result of negative social responses. Being treated as an "other" or a "lesser being" exacerbates the sense of "being an outcast." This type of social pathology contributes considerably to suffering in dementia. The fear of social exclusion is what prevents both people with dementia and some practitioners from embarking on the diagnostic procedure. Although supportive diagnostic disclosure programs exist (Derksen *et al.*, 2006; Moniz-Cook *et al.*, 2008), these do not appear to have found their way into routine practice. For example, Low *et al.* (2017) found an adverse impact on people after a dementia diagnosis. Kate Swaffer, who has experience of living with dementia, described the advice of professionals and others as "prescribed disengagement" (Swaffer, 2015). The findings of Low *et al.* are a powerful reminder of how health professionals can contribute to disempowerment, negative views, and the process of "self-stigma," following a dementia diagnosis.

Cultural variations can also be observed in the experience of dementia. For example, the western emphasis on the dementia diagnosis contrasts with Indonesia, where dementia is often seen as a condition of normal aging, allowing people to remain engaged in their communities (Kristantie *et al.*, 2017). However, not recognizing dementia in a timely manner or not differentiating dementia from ageing can overlook and delay useful existing effective interventions such as those focusing on the essential needs and capacities for pleasure and daily activities (Graff *et al.*, 2006; Gitlin *et al.*, 2010). The reablement intervention described by Jeon *et al.* (2017) contributes to advancing the social health research agenda. The case study demonstrates how people with dementia can be assisted to use their capabilities

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through a comprehensive assessment of person-environment fit, person-directed goal setting, and interdisciplinary team support, in order to maintain a sense of autonomy and independence. Such findings highlight that optimizing the social health of people with dementia requires more than providing opportunities for social interactions.

Dynamics within social networks

Access to social support may contribute to social health (Fratiglioni and Wang, 2007). However, studying the dynamics within social networks suggests that barriers, such as asking for support and a mismatch between demand and supply of social support, can be encountered by people with dementia (Dam *et al.*, 2017). This mismatch was often strengthened by caregivers thinking for other social network members and *vice versa*.

Shared decision making reflects a deliberate attempt to find common ground in understanding and meeting needs of people with dementia, by involving members of the person's network. However, often people with dementia are not seen as having the capacity to make decisions about their own lives. Groen *et al.* (2016) found that people with dementia can actively participate in decision making using both verbal and emotional expressions of communication. A significant obstacle in shared decision making was the tension within social networks, when there were different perspectives and interests of other participants.

Inclusion in social activities in dementia often requires active plans to facilitate this. Mabire *et al.* (2017) did so in a study of small group interventions in a nursing home where social interaction was stimulated. They found that interacting with residents using discussion prompts, such as a theme about Vivaldi's Four Seasons, compared with a group, where reading material was available on the table for participants to use, had a similar effect on social interactions. Thus, social interaction can be enhanced in nursing homes through both active and passive activity opportunities within small groups. Initiating a chorus for people with dementia and their families, with rehearsals and regular choral performances, is another example of how facilitating opportunities for reciprocity within an active stimulating social activity can offer pleasure. Mittelman and Papayannopoulou (2017) found that most of the participants enjoyed the benefits of belonging to a group, engaging in a usual activity together, and learning new skills.

People define themselves according to the places they live and spend their time in. Neighborhood plays an active role in the lives of people with dementia, setting limits and constraints, but also offers significant opportunities that encompass forms of interactive support for people to fulfill their potential and perceived obligations at a local level. Social citizenship stresses the importance of practice within the ordinary lives of people with dementia, and points to the scope of what people with dementia are able and enabled to do in their neighborhood (Ward *et al.*, 2017).

Social and biomedical dementia research: toward improved synergies

Dementia is a multifactorial neurodegenerative syndrome that impacts on multiple aspects of life. Mittelman and Papayannopoulou (2017) note that neurosciences have much to offer in understanding the mechanisms by which music-based interventions can help people with dementia. Current studies suggest that both passive and active musical activities can have a positive effect on the brain. Music can influence all the lobes of the brain; it involves emotional and motor responses; and it can stimulate stored emotional memories (Levitin and Tirovolas, 2009).

Cheng *et al.* (2017) studied the influence of social relationships on health outcomes in a large sample ($n = 4{,}169$). They found that the negative impact of extreme sleep duration was less profound in community dwelling older adults who were married, versus unmarried, and those with strong social networks.

Despite the large heterogeneity of symptom development in the course of dementia, biomedical and psychosocial domains are not often studied simultaneously. The study of Haaksma *et al.* (2017) has attempted to do this, by examining interrelated aspects of functioning over time, on quality of life in people with dementia.

Improving the quality of research that examines social health using rigorous observational and intervention studies, as well as longitudinal designs, is the next step. Importantly, investigating biological aspects of socially orientated creative interventions, such as art, music, dance, and poetry, can further the opportunity to have constructive debate on "rementia" (Kitwood, 1989; Sixsmith *et al.*, 1993), and advance our understanding as to why and how some people with dementia appear to regain "lost function" following supportive psychosocial interventions.

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Conclusions

Using the paradigm of social health suggests that people with dementia might both suffer and benefit from interactions with professionals and others in the social setting, including their families. Papers in this special issue have provided new perspectives, as well as confirmation of what we already know anecdotally, about the social dynamics of dementia. Social interactions are thought to be helpful, but people with dementia describe how interpersonal behavior in their social settings can undermine their sense of self. Moreover, the way in which professionals interact with people during and following a dementia diagnosis can contribute to disempowerment and disengagement, despite post-diagnostic interventions to support people to live well with the condition.

Fostering interventions to allow people to actively engage in reciprocal activities within their social networks can promote social health. Examples include shared decision making, active and passive social stimulation, participation in chorus activities, and facilitating neighborhood contacts. Cultures can learn from each other on how to promote social inclusion within aging and dementia.

Future research needs to move beyond "easy to measure" variables, such as whether or not having a spouse is helpful, or simple counts of social network size, to a more sophisticated understanding of the interactional qualities of social dynamics in dementia. Improved measures of social health can contribute to better models of dementia and inform multivariate and cohort studies. By exploring the role of social health within interdisciplinary dementia research, we can discover more about how people and their carers might live a better life over the course of dementia.

Conflict of interest

None.

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