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Marjolein de Vugt & Rose-Marie Dröes

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INTRODUCTION

Social health in dementia. Towards a positive dementia discourse

Marjolein de Vugt^a and Rose-Marie Dröes ^b

^aDepartment of Psychiatry and Psychology/MUMC+, School for Mental Health and Neuroscience (MHeNS)/Alzheimer Centre Limburg, Maastricht, The Netherlands; ^bDepartment of Psychiatry, Alzheimer Centre, EMGO Institute for Health and Care Research, VU University Medical Centre, Amsterdam, The Netherlands

ABSTRACT

A shift in focus from symptoms and disability towards the capacity and potential of the person with dementia is urgently needed to create a more balanced view of dementia and a more dementia-friendly society, which enables people and their families to adapt to the changes dementia brings in their lives. The new concept of social health suggested by Huber and colleagues seems helpful to make such a shift. In this dedicated special issue, a consensus-based operationalization of the concept of social health in dementia is proposed and several aspects of social health and related dementia care are addressed within the framework of European collaborative projects of the INTERDEM network.

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Introduction

In Western societies, the biomedical view on dementia predominates, with a focus on diagnosis, pathogenesis and finding a cure. This has brought improvements in the early detection of dementia and new insights in the pathology underlying different types of dementia. Much less consideration is given to the role of emotional and social factors in dementia. The influence of the biomedical industry has been accompanied by a negative discourse with a one-sided focus on symptoms and disability and emotionally charged metaphors about dementia that has influenced the public perception (Zeilig, 2014). Dementia is often described in dramatic terms, such as ‘tsunami’, ‘suffering’, ‘burden’ and ‘lack of a cure’. This has contributed to the stigma and feelings of hopelessness in people living with dementia.

An adaptive perspective

A shift in focus from symptoms and disability towards the capacity and potential of the person with dementia is urgently needed to create a more balanced view of dementia and a more dementia-friendly society, which enables people and their families to adapt to the changes dementia brings in their lives and to live well with the condition (Dröes et al., 2016; Vernooij-Dassen & Jeon, 2016). The new concept of social health suggested by Huber et al. (2011) seems helpful to make such a shift. Social health acknowledges that the person can experience well-being despite a medical condition by maintaining a dynamic balance between opportunities and limitations in the context of social and environmental challenges (Huber et al., 2011). This adaptation perspective is not new in the context of chronic diseases (Samson & Siam, 2008) or of dementia (Droes, van der Roest, van Mierlo, & Meiland, 2011) but recently has become more prominent by the proposition of Huber and colleagues to reformulate the WHO definition of health with a focus on the ability of people to adapt

and self-manage when living with a chronic condition. The concept of social health offers a valuable framework for the current fragmented knowledge base and new advances in the field of dementia care (Dröes et al., 2016). It can also be of great significance in de-stigmatizing dementia and offering an alternative frame for the negative discourse that predominantly surrounds dementia (Clarke & Wolverson, 2016; Mitchell, Dupuis, & Kontos, 2013).

A special issue on social health

In this dedicated special issue, a consensus-based operationalization of the concept of social health in dementia is proposed by the Social Health Taskforce of the European INTERDEM network (www.interdem.org). Based on the existing knowledge base regarding factors that influence social health and interventions that can help to improve it, directions for further research and practice to promote social health in dementia are formulated. The three dimensions of social health ‘the capacity to fulfil one’s potential and obligations’, ‘the ability to manage life with some degree of independence’, and ‘participation in social activities’ as described by Huber et al. (2011) were the starting point for this operationalization. Five papers, all collaborations of the INTERDEM network and reporting on studies conducted within the framework of European collaborative projects, subsequently discuss different aspects of social health and related dementia care. Garms-Homolová and colleagues (2016) examined in a large sample of the iBenC project to what extent home care clients in Europe have the capacity to complete the activities that are referred to within the different dimensions of social health by Huber et al. and actually perform these activities despite the fact that many of them may have cognitive problems. They studied everyday tasks such as payment of bills and taking medication and social activities such as participation in accustomed social activities, reciprocal visits with

significant others as well as keeping contact by phone or e-mail. A striking finding regarding social participation is that, particularly people with mild-to-moderate cognitive impairment have limited social resources in terms of their social network and interact mostly only with close relatives and friends. At the same time, the researchers observed that overall cognitive performance has a clear impact on the ability to manage one's own life and to fulfil various obligations at home and in the community. This emphasizes the need for interventions that help people with cognitive disabilities to maintain or enhance their social network and relationships.

In the contribution of Millenaar and colleagues (2016), who used data from the Dutch NeedYD and Nordic multicentre study of quality of life and needs for health care services in young onset dementia, there is a specific focus on the minority group of people with young onset dementia who experience age-specific problems and needs. They identified a unique set of determinants for quality of life in young onset dementia and showed that frontotemporal lobe dementia has more impact on friendship than has Alzheimer dementia. Another finding was that dementia severity was not a significant determinant of quality of life, which shows that in all dementia stages, including advanced stages, people can experience quality of life.

Experiencing social health is not only important for the person with dementia but also for their family who often provide care at home and have to deal with major challenges (de Vugt & Verhey, 2013). Differences in the adaptive ability of caregivers in the context of dementia are addressed in the study of Janssen and colleagues (2016), carried out in the JPND-Actifcare project. They identified different caregiver profiles that explain variability in quality of life, depressive symptoms and perseverance time. It is an innovative study as it provides an integrated view of combinations of caregiver characteristics that offers new opportunities for tailoring interventions to specific profiles and needs of caregivers to promote social health.

In terms of interventions, Mariani and colleagues (2016) focused on the abilities and remaining capacities of people with dementia by highlighting the importance of involving people with dementia in 'shared decision-making' during the care planning process. The study was carried out in the IMPACT project. One of the crucial elements of implementing shared decision-making in nursing homes appeared to be good communication and relationships between staff and families, as well as a positive attitude of family members. Another excellent example of an intervention that promotes social health is the Meeting Centres Support Programme. A key element of the programme is that it gives support to people with dementia and their caregivers in local community centres to promote social participation and integration in the community. Mangiaracina and colleagues (2016) show in a collaborative implementation study JPND-MEETINGDEM, carried out in Italy, Poland and the United Kingdom, that successful adaptive implementation of this originally Dutch Meeting Centres Support Programme is feasible in other European countries by using a step-by-step implementation strategy. Finally, Pinto-Bruno and colleagues (2016) discuss in this special issue that people with dementia can benefit from information and communication technology (ICT) interventions that could help them to maintain, facilitate and create social networks. However, further research on this topic is urgently needed in order to provide insights into which approaches

are the most useful for people with dementia to increase their social participation.

Conclusion

The above studies greatly contribute to raise awareness of the importance of social health in dementia and offer new opportunities for people with dementia and their caregivers to participate in social life. The time is now to promote a more positive view on living with dementia but without neglecting people's losses, adaptation difficulties and possible negative experiences (Clarke & Wolverson, 2016). This asks for a consistent dialogue with people living with dementia and their loved ones to hear their views and to learn about the range and full nature of their experiences.

Disclosure statement

No potential conflict of interest was reported by the authors.

ORCID

Rose-Marie Dröes  <http://orcid.org/0000-0002-4812-1229>

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