

GUEST EDITORIAL

Social aspects of dementia and dementia practice

Social aspects of dementia are becoming increasingly important as part of a wider shift in emphasis from cure to care. This is partly because approaches based on finding a cure have proved far more difficult and complex than originally imagined (WHO, 2016). New evidence on the effectiveness of public health measures, that while incidence is growing as the proportion of older people in society increases its prevalence amongst older adults is actually falling, has also led to increased interest in social dimensions of prevention, lifestyle change, and practical intervention in community settings (Prince *et al.*, 2016; Kivipelto *et al.*, 2017). This, in turn, has led to a rediscovery of the role of supports to people living with dementia in their daily lives, the needs of informal carers, and professional activities that can maintain the social engagement of each party (Winblad *et al.*, 2016). The expansion of practice around person-centered care, beyond traditional institutional settings, has also contributed to a socialized view of how interactions in dementia care are thought about (Bartlett *et al.*, 2017), as has an increased awareness of the effects of the social construction of dementia in the public mind (Biggs, 2018). Most recently, people living with dementia, and particularly with respect to younger onset dementia, have begun to find a voice and to make connections to the wider disability movement (Dementia Alliance International, 2017). Each of these developments, in their different ways, have led to a re-emphasis on psycho-social elements of dementia, its experience, and how that might translate into clinical practice and service delivery.

This special issue begins to address these novel developments with 11 articles (seven original research articles and four systematic reviews) plus an introduction by the guest editors. The special issue is organized around the following key themes: social impacts, personal relationships, and practice interventions. And while any such division runs the risk of underplaying interconnecting themes between contributions, it identifies three levels important in understanding the relationship between wider social factors in which interpersonal interaction and interventions sit, the increasing importance of personal identity and relationships in how we imagine the caring role and specific forms

of intervention that aim to address dementia as currently conceived.

Five of the papers in this special issue arise from larger research initiatives: four (Blair *et al.*, Haapala *et al.*, Nguyen *et al.*, and Sinclair *et al.*) from the work of the Cognitive Decline Partnership Centre (CDPC, <http://sydney.edu.au/medicine/cdpc>), a nationwide Australian research initiative, and one (Szcześniak *et al.*) from a European collaborative research project funded through the EU Joint Programme – Neurodegenerative Disease Research (JPND, <http://jpnd.eu>). The CDPC is supported by the Australian National Health and Medical Research Council in partnership with leading provider organizations and strong involvement from the National Consumer Network and Dementia Australia, to address the applied, social elements, and clinical practice around dementia. The JPND research initiative aims to increase coordinated investment between participating countries in research aimed at finding causes, developing cures, and identifying appropriate ways to care for those with neurodegenerative diseases. The 11 papers in this issue continue on the topic of social health in dementia care discussed by Vernooij-Dassen *et al.* (2018) in *the previous special issue* of the journal and follow a journey through public debate around attitudes and economic considerations and care provision, through a discussion of voice and decision making in practice settings, to aspects of clinical and community support.

In this issue, the first of our three themes, called “Social Impacts,” includes three papers. The first by Haapala *et al.* (2018) reports public perceptions of dementia from the perspectives of people living with dementia, carers, health and social work professionals, and people working in commercial service industries. It examines the relative distinctiveness of each voice and explores age as an additional factor affecting perception. While social inclusion and interaction skills were identified as priorities, traditional public health messaging around health and prevention were less so. Conclusions are drawn on the need for closer attention to the perceptions of the recipients of public health campaigning. The second by Nguyen *et al.* (2018) prompts researchers to include an economic evaluation to the design of interventions

for dementia to strengthen the evidence base in this field. This review supports the view that the complexity of dementia, as a condition which affects people's cognitive and physical capacity and also their behavior, relationships, and social functioning, should be fully considered in intervention design and economic evaluation. In other words, economic evaluation models should explicitly include carers rather than place them with people with dementia in a single category. Each has their individual requirements, even if joined in coping as a couple or family. The third paper by Ydstebø *et al.* (2018) compared longitudinal changes in the quality of life of older people with and without dementia. Changes in quality of life were small despite changes in clinical variables. Their findings indicate that personal experience over time occurs independently of deteriorating symptoms, although lower quality of life was associated with more severe dementia and depression. They also observed that proxy ratings of quality of life are lower than people's own rating. Common themes, therefore, between these three papers include the need to distinguish between the positions of carers, people with dementia, and other groups in the evaluation of perspectival, economic, and quality of life issues.

Our second section addresses personal relationships through four papers. Relationships exist as both a pre-existing context and a factor in decision making around dementia. Conway *et al.* (2018) in their systematic review of relationship change associated with coping with dementia, focus on spousal and offspring relationships. They highlight factors that are important for supporting relationship quality for the people with dementia and the carer separately and as a dyad. Factors such as quality of relationship, responses to stress, and demographic status are found to hold implications for positive and negative influences on relationship quality. Themes identified by Conway *et al.* (2018) incorporated positive and negative facets that impacted on relationship quality. Maintaining relations as a couple or a family emerges as not an easy task without structured support systems. Sinclair *et al.* (2018) report from a qualitative study into the lived experiences of couples living with dementia, with respect to healthcare, lifestyle, and "everyday" decision making. Participants described a spectrum of decision-making approaches influenced by the nature of the decision itself, individual, relationship and external factors. Relationships were often negotiating a balance between maintaining and re-defining couplehood, based on a history of decision-making preferences now challenged by the disease process. Methods are discussed that might

enhance relationship quality and to support joint decision making. Cole *et al.*'s (2018) systematic review focusses on a key decision point and life event: deciding when to move from home to residential care, which still lacks support or clarity. They conclude that decision-making processes appeared to be cyclic, with family carers re-evaluating when might be the time to make the move, sometimes even after a move has been made. Understanding the sequencing, timing, and processes involved help to identify how "optimal" times are constructed for such transitions. Smith *et al.* (2018) explored the Zarit Burden interview as a means of assessing the impacts of caregiving. They identified the direct impact of caregiving, uncertainty around the future, and frustration/embarrassment as factors influencing perceptions of burden. Spouses and adult children were likely to have different burden experiences, with being mindful of positive aspects of caregiving functioning as a protective factor for caring relationships. Each of these papers highlights the importance of relationship in the functioning of caring, both positive and negative, such that impacts on interpersonal relations should be given greater attention in professional interventions. It is perhaps not coincidental that decision making focusses research in this area, given that it often exists at the interface of personal and professional worlds.

A third section includes four papers overtly focussed on practical intervention. When considering appropriate and effective interventions, Kishita *et al.* (2018), in their systematic review of randomized controlled trials of carer interventions, indicate that carers may benefit from psychotherapeutic and cognitive behavioral therapy. They note that, in intervention design and evaluation, little attention had been paid to the diversity of dementia as a condition, the context and the characteristics of the people involved. In support of couples' coping with dementia, Gresham *et al.* (2018) report from an intervention to offer training to dyads of persons with dementia and their caregivers via care provider organizations. Positive results were found in terms of delaying a move into permanent residential care. Blair *et al.* (2018) report similar good results from a larger, multi-center study of rural hospitals, aimed to engage volunteers in providing support to people diagnosed with dementia or delirium or exposed to risk factors for delirium. Reductions in length of stay and readmission were found as a consequence of type of added support. In a multi-center European study, reported by Szcześniak *et al.* (2018), the introduction of new meeting centers as a bridge between diagnosis and residential care was evaluated in four countries. The intervention

proved successful in providing more structured care pathways and post-diagnostic support for people with dementia and their carers.

Taken together, these papers suggest a close, if often tacit connection between social contextual factors, such as public perceptions, economic evaluation and longitudinal life quality, the functioning of personal relationships around care and in decision-making, and the value of supportive and often multidimensional forms of intervention.

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