

The growing challenge of dementia and its impact on patients, their caregivers, and providers

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The October 2017 issue of *Annals of Palliative Medicine* (APM) features the second straight focused issue, this one dedicated to describing the current state of palliative care for dementia in Europe and North America for patients with advanced dementia. The focused issue is guest edited by Dr. Ladislav Volicer, a Professor in the School of Aging Studies at the University of South Florida, who also has faculty appointments at Charles University in Prague and the University of Western Sydney in Sydney.

Dementias are a collective group of disorders characterized by a decline in cognition involving one or more cognitive domains, such as complex attention, executive function, language, learning and memory, perceptual-motor, and social cognition. As defined by the Diagnostic and Statistical Manual (DSM) in the DSM-5 definition, these changes in cognition represent a decline from baseline levels of function, interfere with daily function and independence, do not occur exclusively during the course of delirium, and are not better accounted for by another mental disorder (1). Patients with dementia can have difficulty with behavior, completing complex tasks, language, reasoning, retaining new information, or spatial ability and orientation (2).

Alzheimer's disease is the most common form of dementia and accounts for 60–80% of cases among elderly patients with dementia, whereas vascular dementia is the second most common form of dementia and comprises 10–20% of cases (3,4). As dementia is associated with age, the overall burden of dementia is increasing worldwide with the rising age of the population, particularly among developed countries (5).

In his preface to the focused issue (6), Dr. Volicer, an

international expert on advanced dementia care, explains that Alzheimer's disease and other progressive dementias historically were not considered as appropriate diagnoses for hospice care since they were not thought of as terminal diseases. He accounts his establishment of a Dementia Special Care Unit at the E.N. Rogers Memorial Veterans Hospital in Bedford, Massachusetts approximately three decades ago, which was one of the first such dementia units worldwide, and that introduced the concept of structured palliative care for patients with advanced dementia. In his formation of this dementia unit and in his research and clinical practice since, Dr. Volicer has focused goals of care on quality of life, dignity and comfort instead of prolongation of life for patients with advanced dementia.

The focused issue begins with an editorial from Lloyd-Williams and colleagues on how the care and support of patients with dementia and their families can be improved (7). Kabelka next highlights the need for a comprehensive assessment of patients with dementia and for optimizing communication between providers and family members of caregivers (8). Austbø Holteng and colleagues then report on a study demonstrating that texture modified food may improve nutritional care for patients with dysphagia and dementia (9). Hradcová next discusses ethics and quality improvement in institutional care for patients with dementia (10).

The next set of articles in this issue are original research articles that relate to the Namaste Care Program, a multi-dimensional care program with sensory, psycho-social, and spiritual components intended to enhance quality of life and quality of care. This program, specifically designed for patients with dementia, is intended to reach those who

have severe cognitive deficits, are socially withdrawn and no longer able to benefit from social and group activities, require assistance with daily living, and have limited verbal communication abilities (11). Stacpoole and colleagues described how the implementation of the Namaste Care Program is perceived by families and staff caring for patients with dementia (12). However, Hunter and colleagues report on barriers to implementing the Namaste Care Program in Canada's long-term care system that were identified, included a generally low resource base for long-term care, the need to adjust highly-developed routines to accommodate the program, and reliance on a casual work force (13). In an interview study, St John and Koffman then discuss implementing the Namaste Care Program in a hospital environment and how the program has the potential to improve the quality of life for people with advanced dementia (14).

The "Palliative Care for Dementia" focused issue next features two comprehensive review articles, the first on barriers to palliative care in advanced dementia (15), and the second on the advanced care planning experience of patients with dementia and their caregivers and providers (16). This issue also includes three very interesting Viewpoint articles on palliative care for dementia (17-19), followed by a case study of the effects of the Namaste Care Program on a resident in a skilled nursing facility (20).

To date, articles on neurologic conditions in *APM* have been limited to neuromodulation (21) or to a number of original research articles (22-24) or review articles (25-29) on the neurological effects and treatment of brain metastases. This focused issue on dementia, therefore, is a welcome addition to the broad palliative scope of *APM* and provides vast and diverse information to providers caring for patients with dementia and to researchers in the fields of Alzheimer's disease and other advanced dementias. This issue will also of particular interest for providers and researchers across numerous disciplines outside of dementia since it is well established that patients with multiple chronic conditions and significant cognitive impairments and dementia have worse mortality, institutionalization, and functional outcomes in persons compared to those without cognitive impairments or dementia (30).

This focused issue also could not be timelier. We are now in an era when large registries of patients with dementia are starting to proliferate worldwide. These registries can serve to facilitate research and collect novel epidemiological or quality of care data (31). Although it has long been intuitive that proving and caring for a family member with dementia

is a significant source of stress for loved ones, this issue is also timely given the recent findings that biomarkers of chronic stress, including of neurocognition, are increased among dementia caregivers, and that these caregivers perform poorer on attention and executive functioning tests (32). Thus, the care for rising incidence of persons living with dementia worldwide needs to be considered in the context of both the patients and their caregivers, founding tenants of palliative care across advanced diseases (33).

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Footnote

Conflicts of Interest: The author has no conflicts of interest to declare.

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