



Guest Editorial

Reflections from health systems researchers on nursing practices in dementia care



“Dementia is our most-feared illness, more than heart disease or cancer” (Brainy Quotes, 2019)

1. Introduction

Imagine a world where there were no nurses with expertise in dementia care. We can run this idea through a thought experiment. We'd still have rising incidences of dementia (Fig. 1), running at 55 million people now, rising to 130 million by 2051, alongside extensive associated increases in societal and economic costs. In 2015 this global cost was estimated at US\$818 billion, a 35% increase from 2010. Cost projections for 2018 were set to hit the trillion-dollar mark (Alzheimer's Disease International, 2015).

Although not every patient with dementia needs specialised nursing care, education and training in dementia care has been found to benefit nurses themselves, other healthcare professionals, and the consumers they serve. A recent systematic review by Surr et al. (2017) found that training can enhance staff members' knowledge of dementia care, as well as their confidence, competence, and self-efficacy in delivering dementia care, and lead to improvements in staff-consumer communication and person-centred care. In terms of consumer outcomes, the review demonstrated that specialised education and training could in some instances reduce patient agitation, anxiety, depression and aggression, and enhance quality of life.

Continuing the thought experiment, in a world without professional nurses trained and highly skilled in dementia and associated conditions, large numbers in the dementia population would be at risk of receiving inadequate or even highly inappropriate care. Furthermore, family members would carry a greater caregiver burden due to lack of specialised support.

2. Good nursing care

So what constitutes “good” dementia care in a nursing context? And more specifically, what competencies do nurses need in order to provide high quality care to people with dementia? To answer the first question, we collated four key reports and guidelines on dementia care (Alzheimer's Association, 2018; Guideline Adaptation Committee, 2016; National Institute for Health and Care Excellence, 2018; OECD, 2018) and input them into a word cloud

generator to create a visual representation of the most frequently used words¹ (Fig. 2).

‘Person’ is the most commonly occurring word in the documents analysed. This reflects what Tom Kitwood argued in his seminal book, *Dementia Reconsidered: The Person Comes First* (Kitwood, 1997). As healthcare models transition from practitioner-focused towards person-centred, consumers are recognised as playing a pivotal role in their own care. To the extent that they can, and want to be, people should be kept informed, and included in shared-decision making and care planning. The other frequently occurring words are ones we would expect to see when looking at dementia-management: ‘health’, ‘need’, ‘support’, and ‘live’. Closely following on from this are the provider words: ‘family’, ‘caregiver’, ‘communal’, ‘staff’, ‘nurse’, and ‘provide’. This set of terms highlights some of the key stakeholders involved in caring for those with dementia. Collectively, this emphasises that care goes beyond healthcare institutions and into the community and family home.

To answer the second question, we identified four key competencies from the literature on best nursing practice in dementia. This is not intended to be an exhaustive list, but rather we aim to highlight some of the core elements of providing quality care for people with dementia.

3. Recurring competencies in the context of people with dementia

3.1. Knowledge of dementia

Caring for people with dementia can be rewarding work in many ways, however it can also be very challenging. There are communication barriers, high-dependency care needs, resistant and agitated behavioural responses, and patients' or residents' experiences of disorientation, confusion, and memory loss. In order to mitigate these challenges and provide appropriate, safe and high-quality care, *knowledge* is key. Nurses need to be knowledgeable about dementia as a medical condition as well as the ways in which they can care for those with dementia (Jenkins et al., 2016). They must be able to recognise signs of dementia and deterioration in cognitive functioning and

¹ Common function words such as ‘and’, ‘at’, ‘the’, and key topic words including ‘dementia’, ‘Alzheimer's’ and ‘care’ were removed.

respect, kindness, emotional support, being responsive and attentive, and acknowledging others' vulnerability and suffering. Compassionate care should be provided to every single patient no matter the care setting, the patient characteristics, or the complexity of care required. It is particularly important for people with dementia. Dementia can cause people to feel an array of intense negative emotions such as confusion, frustration, loss of identity, emotional distress, depression and anger (Mayordomo-Rodríguez et al., 2016). People with dementia may be coping with a decrease in their independence. They may be adapting to a transition into residential care and longing for family members. They may also experience confusion from being in an unfamiliar environment and without their regular routine, whether this is in an acute or residential setting. Compassionate care is crucial to alleviating some of these negative emotions and experiences, as well as in developing trusting and caring relationships between nurses and patients or residents. In this special issue, the importance of compassionate care was explored by Petry et al. (2019) who found that care attentiveness (being acknowledged as a person) and responsiveness (being well looked after) were important to the acute care experiences of older persons who had cognitive impairment.

4. The dynamics of caring for people with dementia

While it is valuable to think of dementia nursing care in terms of competencies, this can mask an aspect of the dynamics of the world of care—the longitudinal ways care unfolds in complex settings. Competencies can be construed as a rather static picture of the dynamic work that dementia care encompasses and the dynamic workplaces within which nurses in this field practice. Looking at nurses' work in terms of a reverberating process shows how this caring work flows in complex, hard to master ways. Fig. 3 represents the interactive complexities of the nursing process. It illustrates a journey of learning and discovery that nurses can go through while simultaneously meeting patients' changeable needs.

One main problem with the rising prevalence of dementia depicted in Fig. 1 and the analysis of good nursing practice in dementia care summarised above, is that training cannot keep pace with demand and thus there is a lag effect constantly facing those in this field. It also means that only a fraction of patients are receiving the quality of nursing care that dementia patients deserve. Complicating matters, not much is known about the state of knowledge and training across countries and regions, beyond Europe, North America and Australasia. We also suffer from a lack

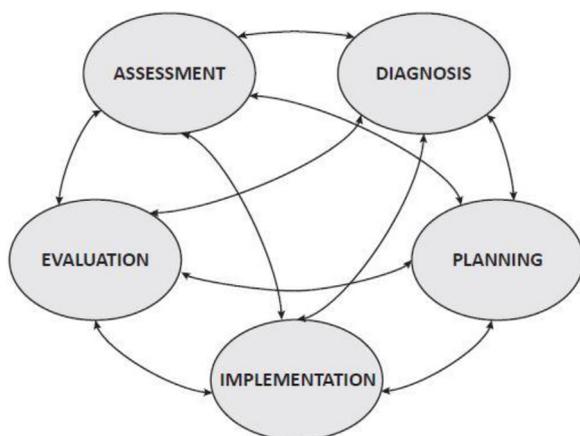


Fig. 3. The nursing process as a dynamic cycle. Adapted from Müller-Staub et al. (2015).

of information about nurses' perspectives on training, what policies are doing to support further training, and the role Universities and other education providers are playing in the development of nurses for dementia care needs in the future. One thing that is clear, however: we have to get this right, given the rising prevalence of dementia captured in Fig. 1.

5. Concluding remarks

We started with a thought experiment. The short answer to our question is that the world would be very poorly placed to care for this vulnerable population if we had insufficient levels of nursing staff in this field to cater for patients' needs. But the truth is, quite a small number of patients with dementia receive the quality of care they need—especially if they fail the postcode lottery in wealthy countries or happen to live in low- or middle-income countries which have less capacity to provide such care. This analysis raises to consciousness how much we should value nurses in dementia care, how we should position health systems to provide for more of them in the future, and how we must do a lot more than we are today to satisfy the need for specialised training to develop awareness, knowledge and skills in caring for this deserving and needful population. It also tells us why this special issue of the International Journal of Nursing Studies on dementia care is so strategically important, and well-timed.

Conflict of interest

The authors declare no conflicts of interest.

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