

My Final Editorial: Whānau Centred Care in Dementia

In 2017 I was fortunate to attend the Australian Physiotherapy Association conference in Sydney. One of the keynote speakers was a professional speaker, Michael McQueen (McQueen, 2018). Michael spoke to the theme of the conference, that of 'Momentum', and said: "*Enduring success and growth for any business today is dependent on building and maintaining unstoppable momentum*"; basically continuing in the same old rut can lead to stagnation and demise. Eight years into my role as Editor of the New Zealand Journal of Physiotherapy, I have reflected on this. The Honorary Editorial Committee has achieved much in this time. We now have a steady flow of submissions enabling three robust issues per year and, as per our mantra, we have assisted and supported many new and emerging writers to publish. We are now Scopus listed. During this time, journal publishing has advanced into the digital world. Eight years ago terms such as Digital Object Identifier System (doi), Publons, Impact Factors, Citations, and H-indexes were mystifying and incomprehensible, now they are part of normal academic-speak. Our journal is not immune to such progress, but to ensure that it continues to be successful we need to maintain our momentum, we need to ensure freshness of ideas and approaches. So with this in mind, I have decided to step down as Editor. This then is my final Editor's editorial. I will thus take the liberty of focusing on a topic dear to my heart, that of carers (informal, unpaid) and support workers (formal, paid) working in the area of dementia care. In this editorial I will propose that physiotherapists need to support, assist and work alongside carers and support workers to achieve best outcomes for persons living with dementia. Physiotherapists working in dementia need to do so within a model of Whānau Centred Care.

Colleagues and I have been researching in this field. In one of our qualitative studies, a support worker in home-based elder care was asked about working with other members of the health care team, for example, physiotherapists. She responded: "*They look at us as if we're just cleaners, they come in, like I've got the uniform, I've got the big badge and I can do this, and oh you've got the vacuum or the duster in your hand.*" (George, Hale, & Angelo, 2016, p9). As a physiotherapist, this was disappointing to hear. And led to our team asking how we can value carers and support workers in elder care for the vital work that they do.

I have argued in the past that as physiotherapists we enable healthy and engaging lives through movement and support, advice and encouragement and that ongoing support of our patients is not only a common ingredient to all physiotherapy interventions but a key one (Hale, 2016). In this editorial I wish to extend this argument to physiotherapists supporting not only patients but also the wider whānau, and in particular support workers and carers, and the particular importance of this in dementia care.

Dementia is an overall term that describes a group of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities (Alzheimer's Association, 2018). Worldwide in 2050,

131.5 million people are predicted to live with dementia (Brookmeyer, Johnson, Ziegler-Graham, & Arrighi, 2007). So into the future, dementia care is likely to be 'bread and butter' work for physiotherapists. Physiotherapy can assist those experiencing dementia to live well, especially by carefully prescribing exercise. Although currently there is no evidence that exercise can prevent or reduce decline in cognitive function (Lamb et al., 2018; Sabia et al., 2017), it is beneficial for many reasons, including for health, falls prevention, to improve or maintain mobility and independence, enhance mood, promote socialisation and reduce pain (Heyn, Abreu, & Ottenbacher, 2004).

Physiotherapists can prescribe exercise programmes and support patients to do them, but in dementia care, most of the support to ongoing involvement in exercise is likely to come from the support worker or the carer. "*Physiotherapy is more than just a sheet of exercises*" is a theme that arose from the Hall, Burrows, Lang, Endacott, and Goodwin (2018) study which explored experiences of people with dementia and their carers of the physiotherapy they received as part of a rehabilitation programme. Participants in this study said that physiotherapists frequently did not think about who should be involved in delivering optimal treatment, and although relatives suggested others, such as day-care services or paid carers, be involved, this was not often endorsed by the physiotherapists. The carer participants felt that being part of physiotherapy delivery was part of their job, and if they were not physically able to assist, that they would want to be part of discussions and decision-making (Hall et al., 2018).

Dementia care includes compensating for diminishing ability to fulfil basic needs; providing assistance in ADL, mobility, safety and function; and prevention, management, or elimination of discomfort (such as pain, constipation, skin deterioration, malnutrition, physical exhaustion, and adverse pharmacological reactions) (Edvardsson, Winblad, & Sandman, 2008; Fazio, Pace, Flinner, & Kallmyer, 2018). But satisfaction of the physical needs can sometimes come at the expense of the psychosocial needs and care can become task oriented and depersonalised. So ensuring the person feels safe and has a sense of belonging and acceptance is crucially important in dementia care; care should thus be person-centred (Edvardsson et al., 2008).

Person-centred care is topical in health care, indeed Physiotherapy New Zealand have just released their model of Person and Whānau Centred Care for physiotherapy in Aotearoa New Zealand (Physiotherapy New Zealand, 2018). Person-centred care is a concept for holistic and individual-centred best-practice care. This notion then leads to the concept of personhood (the quality or condition of being a person). Edvardsson et al. (2008) argue that cognitive decline due to the disease processes of dementia can gradually erode personhood down to nothing. If the person is thought of as an "*empty shell*" or the "*living dead*", social interactions can become unemotional or detached. A belief that "*there is nothing left of the person*" may make the life of the individual with AD seem worthless, which then makes care and the role of the carer meaningless (Edvardsson et al., 2008, p362).

Poulos et al. (2017, p455) proposed the concept of 'reablement' as a means of maximising functional ability to help promote independence in dementia care, of "living well with dementia". This concept requires a collaborative approach both with the person with dementia and with those that support and care for them. This relationship with the person with dementia and their whānau is essential for successful outcome and is central to dementia person-centred care. Thus valuing and respecting the carer and the support worker is crucial to good person-centred dementia care.

Dutton, Debebe, and Wrzesniewski (2012) talk about the concept of felt worth, which they consider a fundamental gauge of social inclusion and respect from others. In the Dutton et al (2012) paper on people who clean hospitals and on the different ways that interactions with others give or deny felt worth, they quote from Perry (1978, p 6): "Critical activities carried out by people playing support roles in organizations is hidden work (such as rubbish collection; hospital cleaning, support worker) base of activity upon which much else must rest. Despite the vaunted technological advances and perhaps even because of them, the lowliest services remain important". I would argue that enablement in dementia thus needs the 'base worker' for optimal intervention outcomes and this thus requires enabling felt worth or valuing of the support worker and carer.

Kadri et al. (2018) explored how the personhood of support workers of people with dementia can be understood. These authors reported that many care staff are not identified as persons in their own right by their employing institutions and that there is a general lack of acknowledgment of the moral work of caring that occurs within formal care work. Kadri et al. (2018) argue that this then diminishes the multifaceted interactions and relationships of care work into a series of care tasks that impede the delivery of person-centred care. These authors concluded that care staff status as persons in their own right should be explicitly considered in quality standards and supported by employers' policies and practices, not simply for their role in preserving the personhood of people with dementia but for staff's own sense of valued personhood.

Why do physiotherapists need to know this information; why is this a subject of this Editorial? In providing physiotherapy we need to better support and value carers and support workers; value their knowledge, skills, and experience, and work beside them to provide best person-centred care. I use the words 'person-centredness' as opposed to 'patient-centredness' deliberately, the term 'person' denotes a "holistic humanness and the equal value of individuals", whereas 'patient' has been described as a "reductionist, stigmatic term that imputes imperfections or undesired differentness to a person and thereby reduces the humanity of the subject" (Kitwood, 1997; Edvardsson et al., 2008, p363).

I predict that dementia care may well be part of physiotherapy's 'bread and butter' work in the future. In upskilling ourselves to meet the benefits and challenges of this work, we need to enhance the personhood of both the person experiencing dementia and the people who support and care for them. As physiotherapists, let us not forget to value and respect carers and support workers in dementia care and ensure we work in a model of Whānau Centred Care.

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