

EDITORIAL

Person-centred dementia care: moving beyond caregiving

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Over a quarter of a century ago, the late Tom Kitwood used his observations of residents living in care homes to begin conceptualisations for person-centred approaches in dementia, which he saw as distinct from a prevailing 'reductionism' which emphasised the medical and behavioural management of dementia. His notion of personhood drew on three types of discourses, that is, theological notions of creation where transcendence and secular humanism are considered; western philosophy and ethics, where the absolute value of each human being obligates each of us to be treated and treat others with deep respect, but where individualism may discount the interdependence of human life; and social psychology as an empirical discipline which places an individual's sense of self within the social group, but where scientific measurement akin to the natural sciences may remain elusive. Kitwood's model drew on the work of Martin Buber to link these three discourses by underpinning good dementia care within relationships, interconnectedness and communication between people. Thus he defined personhood as 'a standing or status that is bestowed upon one human being by others in the context of relationship and social being' (Kitwood, 1997).

Kitwood's early work, set within an institutional context, became strongly associated with his Dementia Care Mapping observational system, which informed the psychosocial intervention that was used for one of the first randomised controlled trials (RCTs) of person-centred care (Fossey et al., 2006). The relational emphasis of his model perhaps provided, for some, the incentive for psychosocial approaches within family care settings, where the most effective interventions were those that were tailored to both the person with dementia as well as their family carer (Olazaran et al., 2010). Meeting these needs might challenge the organisation of care and delivery of support, since professional care is usually oriented towards the delivery of services that are related to the practitioner's specific expertise rather than on the specific needs of the person with dementia and the family. These needs might go beyond the specific expertise of the professionals and the organisations within which they operate. Thus, as research into psychosocial approaches to care have become intertwined with concepts of person-centred care, studies should not only focus on effectiveness, but also need to acknowledge the challenges of implementing person-centred care into daily practice, including organisational aspects and professionals' and patients' and families' perspectives (Moniz-Cook, Vernooij-Dassen, Woods, & Orrell, 2011).

This special issue adds implementation issues and the lived experiences of people with dementia to this emerging literature for both residential and home care settings, whilst also returning to some of the conceptual contributions from humanistic psychology that were outlined by Kitwood (1997), that have yet to be fully studied. Brooker et al. (2015) upscales the work of the aforementioned RCT by Fossey et al. (2006), with an implementation study that achieved the same results, that is, a reduction of antipsychotics use with no harm to residents. They used a manual developed by the original authors to improve fidelity and supplemented the training of person-centred care for staff working in care homes with 'coaches' to support the nine month intervention. These authors note that an important ingredient to successful delivery of the intervention was protected time; in a small number of homes where this did not occur the routine tasks of providing care undermined the delivery of person-centred care. Thus whilst most homes in this study managed to address this major barrier, this remained a substantial barrier to implementation in a small number of homes. These results highlight the importance of attention to the needs of the organisation within a care home – a finding that is further developed by Hunter, Hadjistavropoulos, Thorpe, and

Malloy (2015), who note that organisational support for person-centred care, such as collaboration in problem solving is a significant predictor of person-centred care. They suggest that a specific focus on changing organisational processes to enhance person-centred care may be more beneficial than intervention programmes that simply focus on changing individual staff behaviours.

In the USA, Austrom and colleagues (2015) continue with the endeavour to implement their previous intervention in primary care settings, with a workforce development programme for the delivery of person-centred care for people living in their own homes. Their findings also confirm those described by Hunter et al. (2015), that teamwork and continuity of care are key themes in implementation. The other key implementation theme found in this study was that of building trust and family familiarity, thus emphasising Kitwood's focus of the importance of relationships. In the UK, Maio, Botsford, and Iliffe (2015) found that the implementation of family-centred care by mental health community nurses with dementia experience was perceived as effective, especially in developing rapport and in recognising and supporting needs of dyads of family carers and people with dementia. These results emphasise the importance of relating to needs and challenge the common daily practice in which professionals are considered to be the experts in person-centred care. With the focus on needs, in fact persons with dementia and their caregivers are the experts. Their 'lived experience of dementia' and the creative way in which they overcome some of the obstacles associated with dementia can teach professionals how to protect personhood. Wolverson, Clarke, and Moniz-Cook (2015) coming from a positive psychology perspective, provide empirical evidence taken from the lived experience of dementia to reinforce Kitwood's understanding of transcendence (Kitwood, 1997) and his framework, where notions of love, comfort and attachment (see Kitwood, 1997, Figure 5.2, p. 28) are outlined as important psychological needs in people with dementia. The authors found that positive experiences of persons with dementia related to engaging with life in ageing; engaging with dementia itself; ways to maintain identity and even achieving personal growth. These concepts go beyond those of caregiving. The data indicate that love and comfort might not just be one way, but that reciprocity, allowing people not only to be supported but also to contribute and maintain identity (Vernooij-Dassen, Leatherman, & Rikkert, 2011). These data on the lived experiences of dementia provide the incentive for developing new outcome measures to capture the effectiveness of person-centred care where relationships, interconnectedness and communication between people can be better understood and measured. These outcomes may then contribute to bridging the gap between aims and outcomes in person-centred interventions.

One conclusion we can reach is that person-centred care should not only be directed at compensating for what people with dementia cannot do, but also at facilitating their interests, pleasure and use of their capacities. Thus as research progresses beyond caregiving to embrace the wider concepts outlined by Kitwood, person-centred care may become a facilitator for people with dementia to live life as fully as possible, whether they are supported in the own home or in a care home.

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