

Professor Fiona Poland and Dr Linda Birt University of East Anglia, School of Health Sciences, Norwich, UK

Title: The agentic person: shifting the focus of care

Finding the cause and cure for dementia is the focus of much government rhetoric. Yet in seeking to reduce the impact of dementia for the future we risk failing to take account of recent developments in socially re-positioning people with dementia, which are already reshaping their opportunities for active involvement in their communities of care.

In their paper, Higgs and Gilleard challenge us to consider whether the construct of personhood has real utility for dementia care. They robustly critique the notion of personhood by deconstructing the components of what may make a ‘person’. They examine the four domains of body and the consciousness mind, the socially constructed self, the agentic self and the moral standing of personhood, drawing on the metaphysical and moral theories of person. They go on to discuss how by failing to consider the component parts of personhood Kitwood’s approach to dementia care situates people with dementia as objects of moral concern, with others, usually carers carrying the responsibility to sustain the individual’s personhood. Higgs and Gilleard conclude that professional and policy discourses could more directly address the social positioning of people with dementia by avoiding the term personhood, arguing instead that *‘an alternative approach is to see dementia care in terms of containing and contesting the malign social imaginary of the fourth age’* (page 20). They make the case for not neglecting the study of individual agency and self so that the existing capabilities of people with dementia are supported. We agree that recognising the capabilities of the individual is vital but seek to extend this discussion by exploring ways to support people with dementia in resisting the despair of the fourth age.

Constructing dementia as an illness over which the individual has little control, creates a narrative of deficit in which the person with dementia becomes increasingly dependent on others, not only for personal care but also for their sense of self and their personal status (Sabat, 2002). Research underway in the Promoting Independence in Dementia (PRIDE Study: PI Orrell) uses a sociological lens to highlight the ways in which people with dementia may enact and continue to build social capital, both contributing to, as well as drawing on support that can ensure they remain agentic selves within their social communities and relationships. Attending more closely to the minutiae of their discourses and actions can help us re-evaluate the often subtle ways in which people with dementia continue to strive to reciprocate care and to give to others in their communities however diminished these may appear. The PRIDE study focuses on the experiences of people living with mild dementia, standing on the threshold of a degenerative pathway, commonly envisaged as journey of decline and deficit. To shift the social imaginary of dementia from a form of living in the fourth age, the narrative of deficit needs to be transformed into a narrative of action, even for those living with advanced dementia. By foregrounding narratives of action, we may create care environments based not on a moral imperative, but positively located within reciprocal positive social relationships where the person with dementia and the carer are recognised as partners in co-constructing the care relationship.

A narrative of action can be traced through the embodied self, where the bodily actions of the person can make visible the footprints of past roles and relationships, habits and desires (Kontos, 2005). The pre-reflected bodily actions and gestures of the individual, perhaps in their gait or their mannerisms, are the essence of what makes them a recognisable person. Even when living with advanced dementia, people enact their selfhood, who they were and are, through their bodily actions (Kontos 2012). Acknowledging that people with dementia have an embodied footprint, the pre-reflective essence of their selves in their gestures and

actions, counteracts the risk that opportunities for enacting self are positioned only in others' cognitive domains. Recent work by Godwin and Poland (2015) supports the concept of individual self and agency remaining embodied in the actions of people with advanced dementia, but extends the concept by theorising the emotional self. Opportunities for developing emotional capital may be realised in the structures of autonomy, agency and activity embed within care principles and routines. Drawing on emotional footprints from previously known roles in which they enacted their social status seems to enable narratives of sustained wellbeing for some people with advanced dementia (Godwin & Poland, 2015). This echoes Sabat's (2002) argument that the self in dementia may manifest in very different ways reflecting differing relationships between an individual and their social worlds in which they may deploy emotional capital to remain in active relationships with others and in so doing to sustain an interdependent 'Self 3'. Positioning people with dementia as citizens, Bartlett and O' Conner (2007) argue that simply relying on personhood to characterise quality care mistakenly shifts blame for problematic treatment of people with dementia from the disease process to their local environment, without addressing the influences of wider social forces (2007: 110).

We therefore find considerable agreement with Higgs and Gilleard on the need to contain and contest the malign social imaginary of the fourth age in dementia care. We would add that a way of doing so is to ensure that care environments, whether in community or residential settings, empower the person with dementia to enact and build on continuing opportunities for agency. While the agentic self may change over the dementia trajectory, creating opportunities, while the person is living with mild dementia, for social and emotional independence may provide the embodied and emotional footprints to resist narratives of decline and to realise their potential for capability. This would change the focus of dementia care from personhood providing the moral imperative to care to supporting that person to

remain a citizen with social standing within their community with a stronger voice in their own care.

References

Bartlett, R., & O'Conner, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research, *Journal of Aging Studies*, 21, 107-118.

Godwin, B., & Poland, F. (2015). Bedlam or Bliss? Recognising the emotional self-experience of people with moderate to advanced dementia in residential and nursing care. *Quality of Ageing and Older Adults*, 16(4), 235-248.

Kontos, P. (2005). Embodied selfhood in Alzheimer's disease: Rethinking person-centred care.

Dementia: The International Journal of Social Research and Practice, 4(4), 553–570.

Kontos, P. (2012). Rethinking sociability in long-term care: An embodied dimension of selfhood.

Dementia: The International Journal of Social Research and Practice, 11(3), 329–346.

Sabat, S. (2002). Surviving manifestations of selfhood in Alzheimer's disease. *Dementia: The International Journal of Social Research and Practice*, 1(1), 25–36.