Illness narratives of Alzheimer’s – can these improve care?

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Alzheimer’s disease (AD) results in progressive decline in memory, executive brain function, and behaviour. It is also a significant life event which can be understood within the context of an individual’s lifespan and current circumstances. Although personal narratives of dementia are generally absent in scientific literature, interpretative accounts are thought key to understanding the individual experience of the disease (Beard, 2004). The individual perspective of AD can also be understood in terms of the social meanings or constructs attached to the illness. For example, expectations of normative behaviour by society and carers will impact on whether the behaviour of a patient with latter stage AD is viewed as normal or as a pathology requiring treatment. AD is both a biological disease and a social experience (Vittoria, 1999). In this essay, I will discuss AD from the perspective of the individual rather than the traditional biomedical view. I will examine whether this perspective can improve care of people with the condition.

Individual experience is framed by the psychological, social and cultural context of the individual. An individual’s reaction to a diagnosis will be influenced by their existing
understanding of what AD is and predictions of how it will affect their life. The meaning that an individual will ultimately apply to their memory decline will be a function of their expectations and experience of dementia and concurrent difficulties (Lingler et al., 2006). Memory loss may be accepted as a normal part of ageing in one individual or be of great concern to another (Begum et al., 2012). Individual personality and how adversity has been previously navigated in life will also influence coping style.

Individual perspectives of AD not only help in understanding the subjective experience of AD, but insights can also be used to improve the system of care and to critically challenge societal views of AD. Individual perspectives of AD provide insight into how people experience and navigate the condition. They provide fundamental understandings of how people negotiate death and illness (Vendler, 1994), maintain identity (Beard, 2004), use coping mechanisms (Liptak et al., 2013), as well as the impact of the condition on others (Clare et al., 2012). Interpretative perspectives, such as Kontos’ work on the embodiment of self of patients with AD, counter the presumed disintegration of selfhood in AD and ‘critically challenge the widespread presumption of the loss of agency’ in dementia (Kontos and Naglie, 2007: p.846). These insights offer real hope to both patients and doctors in the face of a difficult diagnosis (Byszewski et al., 2007). This is in contrast to a more ‘mechanistic model of biomedicine which has precluded a systematic examination of the socio-cultural or emotional components of illness’ (Beard, 2004: p.416).

Illness narratives may improve AD treatment from diagnosis to death. Understanding the diagnosis experience may improve coping skills (Aminzadeh et al., 2007) and enhance person centred care (McKeown et al., 2010) and assist end of life planning (Goodman et al., 2013). The individual perspective can also be used to measure the quality of health care itself (Horton, 2008). Outside of health care, understanding and sharing illness narratives of AD can generate solidarity between sufferers and enhance a sense of community (Rodriquez, 2013). Listening to narrative accounts of AD may change societal perceptions of the disease and encourage more political activism from other AD sufferers (Beard, 2004).

Using a social constructionist view of AD may also help avoid inappropriate treatment of behavioural and psychological symptoms of dementia (BPSD). BPSD include a constellation of difficulties such as agitation, aggression, wandering and shouting. These are conceptualised as symptoms using the biomedical approach and thus are often treated in nursing homes with medication such as anti-psychotics (Barnes et al., 2012). These ‘symptoms’, however, can also be conceptualised using constructionist model as unmet need or purposeful attempts at communication. This in turn can generate alternate approaches in dealing with these challenging behaviours and maintain the personhood of the dementia sufferer (Perry, 2005).

In the community, a more holistic view of dementia behaviours may challenge societal norms of behaviour and improve understanding when they occur. It is also hoped that this will improve visibility of patients with dementia and challenge stigma (Gilmour and Brannelly, 2010). Beard comments that ‘when we are receptive to both listening to and valuing what people living with AD have to tell us, we will be well on the way to affording them the space necessary for a visible ... role’ (Beard, 2004: p.415).
AD represents a complex challenge to individuals, society and health care. It causes much distress and fear for some patients, whilst others (and their families) seemingly negotiate the condition with dignity and hope. Iliffe and Manthorpe (2004) comment that the ‘task for health and social care providers is therefore to recognise the diversity of’ patients with AD so that the experience and care of the condition can be improved for all’ (Iliffe and Manthorpe, 2004: p.283).

References


