On becoming a person in society
The person with dementia

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Remember we are struggling to still be the people we have spent our lives becoming.

(Quote from a younger woman with dementia (Harris, 2002)).

Introduction

Historically, the subject of dementia has suffered from poor awareness and understanding, combined with the stigma attached to both mental illness and old age. The stigma of a diagnosis of dementia causes complex emotional responses, and people may go through stages of emotional response to their diagnosis, including: not noticing symptoms, noticing and covering up, or noticing and revealing; confirming or shock; denial, crisis or maximising; disorganisation or adaptation. Emotional responses are frequently the result of fears of loss of autonomy, sense of control, self-esteem, competency, valued lifestyles, social roles or relationships; and one of the most feared losses in dementia is the loss of sense of identity.

The organic disease model recognises that brain dysfunction is extremely varied and extensive. It can be caused by brain injury and from a variety of neurological disorders, and it may be genetic or environmentally induced. In the event of a neuropathology that leads to the loss of cognitive function, biochemical changes that occur vary, depending on the area of tissue that is affected and the cause of that effect. Mechanisms in this process include tissue destruction, compression, inflammation and biochemical imbalances. Dementia, therefore, is not a disease in itself, but a neuropsychological deficit that has occurred as a result of chronic brain disease or encephalopathy (Cheston and Bender, 1999; Wilcock et al., 1999; Neary, 1999). Dementia is used as a specific term indicative of a variety of pathological disorders and is a term related to symptoms, rather than to a specific disease. There are over 100 types of neurodegenerative disorders that may primarily or secondarily affect the brain and cause a dementia syndrome. However, there are four main forms of dementia that are a focus of much of the literature and research: dementia of the Alzheimer’s type; vascular dementia; Lewy-body dementia; and frontotemporal dementia.

Dementia symptoms are usually of a chronic or progressive nature. There is a disturbance of multiple higher cortical function, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement, but consciousness is not clouded. Impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour or motivation (WHO, 1993).
The impairment of memory typically affects the registration, storage and retrieval of new information, but previously learned and familiar material may also be lost, particularly in the later stages. Dementia is more than merely a naturally poor or an impaired memory or general intellectual impairment, there is also impairment of thinking and of reasoning capacity, and a reduction in the flow of ideas. The processing of incoming information is impaired, in that the individual finds it increasingly difficult to attend to more than one stimulus at a time, such as taking part in a conversation with several persons, and shifting of the focus of attention from one topic to another (WHO, 1993).

The diagnosis of dementia

The organic disease model used to explain and understand dementia has had severe consequences on how dementia is viewed within Western society. Cheston and Bender (1999) suggest a range of possible explanations of dementia that have influenced (and still do influence) our understanding and responses to people with dementia. These include dementia as: a disability; deviance; brain damage; a major functional illness; a psychosis; a subjective state; regression; loss; and trauma. This diversity of understanding and explaining dementia has led to fragmentation of academic disciplines and specialisation within fields of research and practice that Cheston and Bender (1999) suggest has hindered cross-frame work.

Dementia has been primarily classified within the psychiatric systems of the International Classification of Diseases (ICD) 10 (WHO, 1993) and the American Psychiatric Association Diagnostic and Statistical Manual (DSM)–DSM IV (APA, 1994). However, actual diagnostic practices vary according to the system being used, time of diagnosis and the sociological and professional position of the person making the diagnosis (Cheston and Bender, 1999). Also, health care professionals use diagnostic labels to classify individuals for both treatment and research purposes. Despite their clear benefits, diagnostic labels also serve as cues that activate stigma and stereotypes that can have a significant and negative impact on interpersonal relationships (Garand et al., 2009).

At each stage of history the medical establishment (and the population) accept the textbook definition of their time, and diagnosis depends on an arbitrary dividing line drawn on some point in a continuum of disability, which may be viewed as an evolving concept (Berrios and Freeman, 1991: 1). Berrios and Freeman (1991) propose a shift towards the ‘creational’ approach to diagnosis, acknowledging that there is ‘no such thing as the final description of a disease’. Its clinical boundaries, symptom-content and even anatomical descriptions are no more than temporary scripts, taken from the ongoing medical discourse. That is, the creation of disease can also be viewed as social phenomenon. Once a name is accepted, it quickly comes to dominate the social reality of the disease, and the flavour of the name can make a difference to how the disease is perceived and acted on (Shenk, 2001). In other words, definitions of dementia are social constructions, imposing order upon data in a particular and selective way, and these constructions act to emphasise particular ways of thinking about or addressing dementia, often ignoring other viewpoints (Bender and Cheston, 1997; Gubrium, 1986; Kontos, 2004, 2005; Sabat and Harré, 1992). Gilmour and Brannelly (2010) propose that assimilating contemporary representations of dementia requires the discarding of historically dominant elite and authoritarian accounts of the experiences of people with dementia, and possibly discarding the historically burdened term of dementia itself.

It is often assumed that people with dementia are not coherent or lucid enough to be able to express a view on many aspects of their lives and are consequently marginalised and silenced. Until recently, people with dementia were very rarely asked for their opinions or judged to be fully legitimate persons, and older people with memory loss are often silenced by their own fears of humiliation. Constructions of dementia were to portray that the memory impairment caused by cognitive deficiencies will lead to a steady loss of selfhood. However, many now argue that this is inherently incorrect and that selfhood persists even with severe dementia (Kontos, 2004, 2005; O’Connor et al., 2007; Phinney, 2002). Kontos (2004) proposes that selfhood persists because it is an embodied dimension of human existence and that the insistence...
that selfhood is the exclusive privilege of the sphere of cognition has its origins in the modern Western philosophical tradition that separates mind from body, and positions the former as superior to the latter.

Kontos (2005) challenges the mind/body dualism that underlies the assumed loss of selfhood in the current construction of Alzheimer’s disease, and advocates a theoretical framework of embodiment. She argues that people with cognitive impairment are actively involved with the world through their embodied way of ‘being-in-the-world’, i.e. they interact meaningfully with the world through activity and engagement, rather than contemplation or reflection. The central claim of Kontos’s work (2004, 2005) is that selfhood is embodied and characterised by an observable coherence and capacity for improvisation that is sustained at a pre-reflective level by the primordial as well as the socio-cultural significance of the body.

**Perspectives of people with dementia**

Pioneers of person-centred approaches to working in the field of dementia have been instrumental in calling for recognition of an enduring personhood and arguing for the centrality of the person, providing evidence that the emotional life of people with dementia is still intact despite often severe cognitive deficits (Feil, 1993; Killick and Allen, 2001; Kitwood, 1988, 1989, 1990, 1993, 1997; Kitwood and Bredin, 1992; Marshall, 2001; Morton, 1999; Sinason, 1992). It is now recognised that the symptoms and behavioural changes associated with dementia do not arise purely from neuropathology, but from a dialectical interplay between neuropathology and the person’s interactions with others within their environments; from their personal histories; from how they themselves are perceived within their social contexts; and from sustaining a sense of continuity despite changes resulting from dementia (Hughes et al., 2006; Kitwood, 1997; O’Connor et al., 2007; Phinney et al., 2007). Narratives of people with dementia now clearly reveal them as people who are still engaged in life and have capacity to participate fully in living and enjoy meaningful relationships with others.

It is increasingly advocated that a ‘first-person’ account must be taken into consideration when trying to understand the experiences of people with dementia (Keady et al., 2007a, 2007b; Page and Keady, 2010; Phinney et al., 2007). Ambassadors of people with dementia are now par for the course and have become the mouthpiece for those who have not been enabled or are no longer able to tell their stories in a public arena. Christine Bryden (2005) is one such ambassador and was one of the authors reviewed in a meta-ethnographic analysis of 12 autobiographies written by people with dementia between 1989 and 2007 by Page and Keady (2010).

Bryden (2005) was diagnosed with Alzheimer’s disease when only 46 years old. For her, the prognosis was horrific and as a consequence she wrote her first book, *Who will I be when I die?* (Boden, 1998), in which she expresses her shock and horror at the diagnosis and prognosis, and her fear and anxiety about a disease that she believed would deprive her of her identity and personality. Rather than accepting the passive role of a person with dementia, Bryden has become an internationally recognised speaker on the personal experience of having a dementia diagnosis (www.christinebryden.com). The internet provides a vehicle for people to share their experiences of living with dementia through online journals and chat rooms and is now used widely by people with dementia and their significant others.

In some studies, living with dementia is presented as a positive narrative by the person with dementia, where only minor problems are expressed and where abilities and contentment with life, and being valued, rather than losing one’s cognition or identity were emphasised as central in their experience (Steeman et al., 2007). Steeman et al. (2007) suggest that, superficially, a positive narrative may be understood as a lack of awareness or as denial due to cognitive loss. However, more in-depth analyses of these narratives reveal that people with dementia are constantly balancing their feelings of value and
worthlessness and struggling to remain someone of value. This struggle is primarily prompted by threats posed by progressive cognitive deterioration caused by dementia and by the person’s interactions with others (Steeman et al., 2007).

The meta-ethnographic analysis of autobiographies written by people with dementia conducted by Page and Keady (2010) demonstrated how an awareness of change reflected the intuitive knowledge that something was ‘not right’, and all authors went through a process that eventually led to a diagnosis of dementia that was frequently described as ‘arduous’. They identified the need to hold on to some sense of who they were, sustaining continuity over their identity. Their presentation to others was used as a means of facing an overwhelming and common ‘enemy’ (dementia). The very act of writing their stories offered an opportunity to reposition themselves and resist the disease process (Page and Keady, 2010). In most of the autobiographies, the authors felt that they had a ‘duty’ to bring attention to the lived experience of dementia and to ‘speak up’ on behalf of others who are not able to do so (Page and Keady, 2010). This supports Phinney’s (2002) point that those who have made an effort to tell the story of their personal experiences of dementia are exceedingly aware and articulate and are able to step aside from their immediate involvements to reflect on their lives. Much less is understood about the illness narratives of those whose awareness is fluctuating, and what these narratives reveal about the meaning of living with dementia (Phinney, 2002).

Narrative accounts of the experience of dementia can present as a complex mix of new, revised and disconnected storylines that combine to create a person’s sense of self and identity (Page and Keady, 2010). However, for many people, their dementia awareness fluctuates. Symptoms may be obvious, or vague and inconspicuous; symptoms may be forgotten, or they may be entirely absent for the person (Phinney, 2002). This makes it difficult for people to articulate a narrative understanding of what is happening in their lives, so the narrative of dementia becomes shared as others join in its telling (Phinney, 2002). In later stages it may become a narrative of chaos that is all but impossible to articulate (Phinney, 2002). Mills (1997) also noted that, for some people with dementia, the sense of narrative identity began to dissolve as their illness progressed and their stories faded from memory.

Keady et al. (2007a, 2007b) suggest that detailed autobiographical knowledge of the person with dementia is crucial to understanding the cognitive and life changes that take place, especially when life storylines are misremembered and/or mis-sequenced. In other words, it is important that the person with dementia’s narrative identity is primarily located in the ‘here and now’, with the past subject to re-editing and revision at any time in the process of its telling. The experiences of narrative breakdown reveal that human beings are not isolated units and stories are told in and through dialogue with others (Phinney, 2002). Also, the narrative of chaos is evidence of how the experience is in some way beyond the power of language to convey (Phinney, 2002). This supports positing a shift of the discourse on selfhood in dementia towards a greater recognition of human embodiment and critically challenging the presumption of loss of agency, i.e. loss of capacity to act independently, due to cognitive impairment (Kontos, 2004). Where the person may struggle to describe their experience in words, the body’s actions may tell a clearer story (Phinney, 2002).

Dementia and loss

One of the themes in the meta-ethnographic analysis conducted by Page and Keady (2010) was that of experiencing loss, where all the narratives were stories associated with the anticipated and actual loss of the sense of ‘who one is’. At the heart of dementia is loss, and the narratives of people with dementia reveal the very real experiences of loss that occur with dementia (Chesten and Bender, 1999). The many losses experienced include: losing track of conversations; losing track of time; forgetting names and events; and loss of practical skills, making it difficult for persons with dementia to understand their circumstances or to hide their problems from others, causing frustration, uncertainty and fear.
These narratives also reveal transitional experiences for people with dementia and their significant others, and since the late 1980s there has been a new emerging view on the experience of dementia, where the individual perspective of the person with dementia is being stressed. Within this new perspective has come a more developed understanding of both the experiences and emotional needs of people with dementia (Kitwood 1990, 1993; Kitwood and Bredin, 1992; Miesen, 1993, 1997, 1999; Normann et al., 1998, 2002, 2006). An awareness context for people with dementia exists and can be accessed and scripted in circumstances related to care practices and a concept of loss (Miesen, 1997, 1999; Page and Keady, 2010). There is also growing literature on the applicability of attachment theory to the behaviours and response to loss and illness for people with dementia. Bowlby’s (1997) attachment theory has provided a conceptual and empirical framework for examining some behaviours of people with dementia and provides a means of interpreting them in terms of responses to loss (Browne and Shlosberg, 2005, 2006; de Vries and McChrystal, 2010; Jones, 2004; Miesen, 1993, 1997, 2006). Miesen (1993, 1997) argues that his clinical observations and research, plus the research of others, have proven that people with dementia of the Alzheimer’s type still respond to their illness, even after their ‘illness-insight’ has disappeared, i.e. emotional responses to their experiences remain throughout the dementia process (Miesen, 1999; Mills, 1997).

This ability of people with advanced dementia to respond meaningfully to others in some situations has been identified by researchers in the field (Kitwood and Bredin, 1992; Normann et al., 1998, 2002, 2006; Sabat and Harré, 1992) — not only through the use of dynamic psychotherapy that has been used in research on this aspect (Hausman, 1992), but also through the ‘kind care’ that may be part of the normal practice of formal care-givers in nursing and residential homes. Treating people with dementia as legitimate persons to be validated and listened to can have an impact on a person with dementia in that some lucidity is briefly restored when the person is treated with a high level of kindness and gentleness (Normann et al., 1998, 2002, 2006). Kitwood and Bredin (1992) anecdotally report that people show ‘remoteness’ when a conscious connection is established with a carer. These care events, centred on the individual, may slow down and limit the effects of the process of dementia (Kitwood, 1997).

There are many anecdotal reports of carers relating episodes of the person with dementia unexpectedly speaking or acting in a way that surprises the carer and indicates that that person may be more aware of his environment and situation than assumed. Such episodes have been referred to as ‘episodes of lucidity’ (Aakerlund and Norberg, 1986; Norberg et al., 1986; Normann et al., 1998, 2002, 2006). Data from five interviews (over a period of two weeks) with a woman with dementia showed how lucidity is promoted by supporting the person with dementia using concepts of confirmation and communion. Support was given by sharing the person’s view, repeating and reformulating the person’s utterances and not emphasising errors (Normann et al., 2002). Normann et al. (2002) also showed how, when the researcher made demands on the person with dementia, the response was to go from lucidity to nonlucidity. Using this approach, communication can be understood as more than just transmission of information, but rather as a certain way of relating to the other (Normann et al., 2002).

Bleathman and Morton (1992) reported experiences similar to those described above when using validation therapy with people with dementia. Examples of the use of reminiscence, where people with dementia have unexpectedly told carers something about their past that was confirmed by their relatives have been described (Bright, 1992; Sabat and Harré, 1992). Jansson et al. (1993) and Kihlgren et al. (1996) report that people with dementia revealed more of themselves to carers who spoke the person’s native language and provided them with calm, loving care. Furthermore, Normann et al. (2006) found that more residents with ‘episodes of lucidity’ participated in outdoor walks than those without, speculating that having walks outdoors with the key care provider is an activity that brings the resident close to the care provider; it most likely also implies body contact, like walking arm in arm. It also implies the possibility that experiencing the natural environment may have a spiritual component that has been as yet unexplored. Many of these studies are small, but accumulatively they provide evidence.
that people with dementia retain emotional responses to events that occur in their lives through all stages of the illness.

**Maintaining cognitive ability through education and training**

Although a burgeoning research literature has emerged within the field of dementia since the early 1990s, very little research has been conducted on health promotion through education for people with dementia (Richeson et al., 2007). In a study that examined the effects of a 13-week adult education class for older adults with early-stage dementia titled, Health Promotion for the Mind, Body, and Spirit, conducted in a normalised, dignified and non-stigmatised environment, Richeson et al. (2007) found that older adults with early-stage dementia were still interested in learning, growing and making connections.

Despite the severity of memory difficulties, many aspects of memory remain relatively intact, particularly in the early stages of Alzheimer’s disease. The growing emphasis on early detection and diagnosis of dementia has meant that cognition-focused approaches have been increasingly adapted to the needs of people with early-stage dementia (Clare, 2003). There is a long tradition of cognition-focused intervention in dementia care (Clare and Woods, 2004) and a growing research literature on the possible value of interventions to improve memory functioning for this group.

The range of specific interventions and research methodologies on improving the cognition for people with early-stage dementia is large and varied and includes approaches such as: memory intervention training (Hawley et al., 2008; Troyer et al., 2008); spaced retrieval memory training (Bourgeois et al., 2003; Cherry and Simmons-D’Gerolamo, 2004; Cherry et al., 2009; Hawley and Cherry, 2008; Hochhalter and Overmier, 2005; Hopper et al., 2010; Moore et al., 2001); computer-based memory training (Schreiber et al., 1999) and mental aerobics (Hayslip et al., 2009); episodic memory (list recall, face-name association, text memory) (Belleville et al., 2006); formal-semantic therapy (Bier et al., 2008); and many more.

Cognitive training using the theoretical framework of ‘errorless learning’ as a guiding principle has been the focus of a large number of such studies (Akhbar et al., 2006; Clare et al., 2000; Clare et al., 2002; Dewar et al., 2009; Dunn and Clare, 2007; Haslam et al., 2006; Haslam et al.: 2010; Jokel et al., 2010; Kessels and Olde Hensken, 2009; Mimura and Komatsu, 2007). Errorless learning concepts were adapted from research on animal models to aid learning in people with learning disabilities and people with acquired brain injury (Clare et al., 2000). Errors made during learning are strengthened in implicit memory. Normally, explicit memory serves to eliminate these errors, but in individuals with explicit memory decrements (e.g. due to amnesia, dementia, or, to a lesser extent, ageing), these errors are more likely to affect learning and memory (Jokel et al., 2010). The technique is based on the principle that it is difficult for people with impaired memory to remember and correct errors made while trying to learn something (e.g. calling someone by the wrong name and then tending to remember the wrong name, rather than the correct one). Therefore, learning is more efficient if errors can be avoided during the initial learning process (Evans et al., 2004).

Mimura and Komatsu (2007) maintain that error elimination during learning sessions is essential for favourable outcomes and it has been speculated that some of this success on cognitive rehabilitation may be due to the indirect result of methods that keep errors to a minimum (Clare et al., 2000). Clare et al. (2000) suggest that errorless learning offers one important parameter that may be very beneficial for people with dementia of the Alzheimer’s type. That is, errors are avoided or minimised and participants have the opportunity to experience success at every stage of the learning process. This lends support to the findings of Richeson et al. (2007): where it was shown that providing older adults with early stage dementia educational opportunities in a normalised, dignified, and non-stigmatised environment has the possibility to influence their self-efficacy, mood and mental status. It also supports the experience of ‘remediation’ occurring in advanced dementia, when approaches to care are based on not emphasising errors and on treating people...
with dementia as legitimate persons to be validated and listened to (Hausman, 1992; Kitwood and Bredin, 1992; Kitwood, 1997; Normann et al., 1998, 2002, 2006).

It is not possible to draw firm conclusions about the efficacy of individualised cognitive rehabilitation interventions for people with early-stage dementia, due to the lack of randomised controlled trials in this area; however, indications from single-case designs and small group studies are cautiously positive, i.e. errorless learning offers valuable benefits for at least some people with memory impairments when teaching certain types of tasks, but the benefits are not evident for all groups (Clare and Woods, 2004; Clare and Jones, 2008).

The spiritual lives of people with dementia

The search for meaning and purpose during stressful life events knows no religious or spiritual borders, even among the non-religious and non-spiritual, and, for people with dementia, purpose and meaning are found in many different ways. Religion or spirituality has been found to provide solace by inspiring feelings of hope, strength, security, or guidance, and has helped with acceptance of the disease or with relieving anxiety and fears (Snyder, 2003).

As discussed above, people with dementia have been shown to have rich and powerful inner lives, particularly in the realm of feeling and emotion. As already established, the core of their being (the person) still remains, and knowledge and understanding of the personal spiritual beliefs can be a way of connecting with that person. Persons with mild-to-moderate dementia have been found to have higher than average levels of religious activities and intrinsic religiosity than do persons with cancer or hypertension (Koenig et al., 1988a, 1988b) and, for people with dementia, personal spirituality was exemplified as religiosity (Katsuno, 2003). Those with early-stage dementia often find personal spirituality and its internal meanings important in coping with their life situations, i.e. spirituality is associated with their perceived quality of life (Katsuno, 2003; Page and Keady, 2010). People with early-stage dementia may retain a strong faith in God and still experience all areas of religiosity and use religion for coping with their illness and to find meaning and purpose in life (Katsuno, 2003).

In most of the accounts, Page and Keady (2010) found that thoughts about death were present, often significantly so, but death itself was alluded to through the use of metaphor, and most often loss was described in terms of the loss of quality of life. The stories shared by each of the authors demonstrated that the ‘reconfigured – and reconfiguring – sense of selfhood’ appeared to be influential in retaining the possession of religious or spiritual beliefs from which the strength to stand up and bear witness was found. Over half of the authors included in the meta-ethnographic analysis expressed strongly-held religious beliefs and the narratives resonated with the humanitarian and moral beliefs of the writers (Page and Keady, 2010).

In The Forgetting, Shenk (2001) reminds us that, in the case of dementia of the Alzheimer’s type, in the early stages it is not that the person with dementia forgets what they have learned or experienced, but that they do not form a memory of the event. Consequently, the person lives only in the relative now. Bryden confirms this experience when she moves from her anxious stance, early in her dementia experience, of asking; ‘Who will I be when I die?’ (Boden, 1998), to, ‘I know who I’ll be when I die’ (Bryden, 2005). She bases this on her Christian faith and also the discovery of the Buddhist principle of being in the ‘now’, a concept that became the most important (and often only) time that could be considered. ‘My spiritual self exists in the “now”, with no past or future’ (Bryden, 2005: 160). This understanding of a fundamental Buddhist concept allowed her to begin to live in a manner that she had never before considered. Her life became more focused on the meaningfulness and sensitivity of relationships, moving from the fear and anxiety of loss of control.

Conclusion

Dementia remains a condition that is imbued with stigma and fear, despite the promotion of raising awareness and understanding about the illness and the development of person-centred approaches to being
with, and communicating with, people with dementia. Concepts of rehabilitation and person-centred care in early-stage dementia point to the need for interventions that are relevant to everyday life, with the potential to optimise functioning and wellbeing, and support selfhood and social involvement (Clare, 2003). It is important for people living with dementia to sustain relationships that are pivotal to maintaining good quality of life and assist in mediating the significant social losses being experienced in the person’s everyday life. Errorless learning may offer very valuable benefits; however, the majority of cognitive training interventions are commenced following diagnosis, and formal diagnosis, even for those who are experiencing severe cognitive loss, remains a significant problem for people living in the community (Bamford et al., 2004; 2007; Koch and Iliffe, 2010).

Terms used to describe spirituality are closely linked to descriptions of person-centred approaches to people with dementia. These encompass the wide-ranging discussions on: meaning and purpose in life; connectedness (to be associated with others and the world); nature and beauty; love, belonging, respect; transcendence; belief and faith; inner strength and peace; life and spirit; and self-discovery. In the biographies analysed by Page and Keady (2010): in many research papers and in the work of pioneers in dementia research, these terms are the mainspring of the new emerging understanding of dementia as experienced by the person and support the person/relationship-centred approaches to being with, working with and caring for, people with dementia. These understandings lead to new possibilities in increasing quality of life for people with dementia through supported learning experiences.

References


Dunn J. and Clare L. (2007) Learning face


