Challenging the discourses of loss: A continuing sense of self within the lived experience of dementia

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The journey of becoming, of leaving behind previous perceptions of who we are, is common to us all, as part of our life’s narrative. Yet those of us diagnosed with dementia fear a different journey of loss of self, exacerbated by social commentary, such as, ‘She’s no longer there’. Since my diagnosis with dementia in 1995, I have published several autobiographic narratives (Bryden, 2005, 2012, 2015a, 2015b) and reflections (Bryden, 2016; Bryden & MacKinlay, 2002), as well as a literature review on counselling and psychotherapy for people with dementia, when this was a new concept (Bryden, 2002).

In my doctoral research, I used autoethnography, in the form of a subjective narrative, to explore a key issue emerging from this body of work: loss of self in dementia. Autoethnography provides a valuable theoretical framework for engaging further with this theme, as it uses the techniques of autobiography and ethnography to analyse my own lived experience (auto), in order to shed light on a continuing sense of self throughout dementia (ethno). It enables me to draw on my own work, as well as engage with selected literature, for deeper cultural analysis and interpretation. Importantly, by analysing a key issue arising from the experience of a cultural group (people living with dementia) of which I am a member, I have complete member researcher status (Anderson, 2006; Ellis & Bochner, 2000) and can provide an insider’s perspective.

Proponents of autoethnography write of ‘trying to preserve or restore the continuity and coherence of life’s unity in the face of unexpected blows of fate’ (Ellis & Bochner, 2000, p. 744). This goes to the heart of my efforts to challenge the threat to the continuity and coherence of
my life’s unity in the face of a diagnosis of dementia. This methodology is important to establish an understanding of a continuing sense of self in dementia.

Diagnosis had disrupted my story of a future high-level career reliant on continued cognitive function. It confronted me with the dominant biomedical discourse of dementia of increasing brain damage leading to loss of all faculties, and I became subordinate to the power of the prognosis that I would gradually lose my sense of self and become totally dependent upon others. I felt that my story had become ‘re-interpreted, re-packaged, and re-presented . . . to conform to the objective and scientific basis of medicine’ (Clark, 2001, p. 195). In addition, the psychosocial discourse of dementia being a relational as well as a neurological disability focuses on improving care of people with dementia, due to their increasing loss of capacities.

The pioneering psycho-gerontologist, Tom Kitwood (1997), introduced the term personhood: a standing or status bestowed upon one human being, by others, in the context of relationship (p. 8). However, philosopher Stephen Ames (2016) points to the risk of defining ‘personhood as an attributed status, as it makes personhood vulnerable if the person is not recognized, indeed not recognizable’ (p. 127). Bestowal of personhood implies a one-way relationship, in which the caregiver actively bestows, and the person with dementia passively receives.

Person and personhood are terms used to imply having certain capacities and attributes, as observed by others. In my work, written from an insider’s perspective, I use the term ‘self,’ as expressed by first-person language and defined in the social constructionist literature as the ‘self of personal identity’ (Sabat, 2001, p. 17). Self expresses how I have a mental representation of myself as the centre of my conscious agency, necessary for me to relate to others, and to think about thinking, deciding and doing (Brown, 1998, p. 108). This self has a mental feeling of ‘I’ as a continuous whole throughout my life, which is making sense of the world, interacting with my changing physical, emotional and spiritual environment.

Despite my diagnosis, my subjective sense of self remains, perceiving and interacting with my changing material, social and spiritual environments. I am not simply a bundle of attributes; there is much more to my life, relationships, and sense of unity, shaping my personal identity (Bryan, 2016, p. 13). I am far more than a deteriorating self in an increasingly empty shell of a body, with disappearing neurones and neuronal pathways.

Another major challenge in my reflective writing is decreasing vocabulary and grammar. There is no thesaurus that will help me find the word or phrase that has become elusive, as all I have left are vague concepts, so cannot search for the synonyms or antonyms. In my head ‘a string of pictures has formed, but the words for those pictures no longer make their way into [my] consciousness’ (Bryden, 2005, p. 118). Although I rarely find what I am searching for, I can still reflect on meaning and explore my continuing sense of self, I am still Christine, who can search for meaning within her lived experience of dementia, and give an authentic experiential account of dementia to provide alternative insights into the discourses of loss of self.

Narrative is an important methodology, described as a ‘qualitative or interpretative research method . . . [in which] researchers study things in their natural settings, attempting to make sense of and interpret phenomena in terms of the meaning people bring to them’ (Moen, 2006, p. 61). This aligns with my purpose in searching for meaning from within the setting of my own lived experience, and reflecting on the phenomenon of perceived loss.
of self. Thus, narrative is particularly useful, in order to transform the understanding of ‘that experience for [myself] and others’ (Clandinin & Roziek, 2006, p. 42).

Narrative is also described as ‘a crucial conceptual category for... depicting personal identity’ (Hauerwas & Jones, 1989, p. 5), and as revealing the self as a whole, in its indivisible unity of body and mind (Crites, 1971, p. 85). This resonates with an exploration of a continuing sense of self within the lived experience of dementia. I examine my ‘inner history of self,’ which gives a very different perspective to ‘the outer history of things’ (Neibuhr, 1941, pp. 33, 30). From this inner perspective, my narrative exists within a disturbed sense of time, rather than chronological time, thus it is not based on objective facts, but on a subjective search for meaning.

Before my diagnosis with dementia, I saw the world through the lens of my intellect. Being highly intelligent was so much a part of who I was. ‘My brain was my identity’ (Bryden, 2015a, p. 139). My cognition was threatened by my diagnosis in 1995, and the discourse of loss of self led to an overwhelming existential fear of future non-being, described as ‘the anxiety of not being able to preserve one’s own being’ (Tillich, 1969, p. 47). Clinically, people with dementia become described by a set of standard cognitive defects, where the ‘clinical approach assumes that our brains, our life histories and our individual life experiences are all the same’ (Bryden, 2015b, p. 204). ‘We have lost not only our identity, but also our diversity. Everything that once made us a unique... individual with value to society, has been lost’ (Bryden, 2015b, p. 274). My sense of self cannot be measured by examining neurological defects, as I also have thoughts, images and feelings, although I am losing the ability to express these clearly. Importantly, I know who I am, and have the ability to distinguish self from non-self.

In today’s Western society, having a thinking self is commonly associated with the brain, giving rise to the view that dementia due to increasing brain damage means a loss of self. Perspectives on loss of self in dementia have come from outside observers, who can only imagine whether this actually occurs; they cannot know. My sense of being an embodied self includes living with dementia, as this is who I am and who I will be until I die. The view of outsiders as to whether I am still ‘me’ presumes that I have forgotten who ‘I’ am, and that with a loss of language and of recall, a sense of self is lost. However, my sense of self continues, despite me being unable to keep track of memories because of ‘the erosion of the temporal glue’ (Post, 2006, p. 225). Even if my recollection of taking my tablets a few moments ago has gone, or I cannot find the word for tablets, I still exist as ‘me’ in the present moment. My sense of being an embodied self continues within dementia: I see the world through my own eyes, and it is ‘that part of me when I am with myself’ (Reinders, 2008, p. 21). I suggest that this remains intact in dementia, despite linguistic, thought-ordering and recall dysfunction. Although I am losing capacities to express my sense of self, I still have unique personal characteristics, which are not lost because of failing cognition. Even if I have lost a reliable connection with my past, and to the future, I am the Christine who, even without language, has the feelings of ‘What is happening to me?’

My constant struggle is not only to battle with my neurological deficits, but also with the external discourses of loss. Recognising my continuing sense of being an embodied self within dementia is important for regarding me as having a valid subjective perspective. As Post writes, ‘What is morally relevant is the experience of subjectivity, of myself as a subject in the sense of being conscious of self as self’ (2006, p. 230). My sense of being an embodied self, sitting here writing and editing this article is the same embodied self that sat here a moment ago, even if I cannot recall that moment. This is my sense of being
a continuing embodied self, whom I am, then and now, and my damaged brain has not diminished this sense of being present.

An important feature of dementia is problems with recall of past events, yet the neurological architecture for this difficulty is not well understood. We appear to perceive, learn, and manipulate information in an interaction of neuronal pathways to interpret, record and perceive events, with complex patterns for storage and mechanisms of access in a dispositional network of maps and images (Damasio, 2010, p. 135). Given this complexity, at least some of these neuronal pathways might persist in dementia, so as to account for the retention of procedural (knowhow), as well as aspects of semantic (conceptual) memory. This might explain the so-called ‘lucid episodes’ observed by caregivers (Aquilina & Hughes, 2006, p. 145). What is feared most in dementia is the loss of episodic memory, or an ability to recall past events, as the outsider’s perception is that this means loss of self. However, this assumes that my sense of being an embodied self is dependent on recalling what I did, rather than on knowing who I am. In addition, not all of episodic memory is lost, and it seems that within my neurological architecture, prompts can provide access to neuronal pathways.

Among modern philosophical accounts of the embodied self are arguments for causal reductionism, in which I am ‘nothing but’ my neurones. This gives rise to the conclusion that dementia due to brain damage indeed leads to loss of self, which has been a dominant position, particularly among atheistic scientists. The Christian philosopher Nancey Murphy (1998) developed the concept of nonreductive physicalism, which suggests that I am far more than ‘nothing but’ my neurones, and have a sense of self.

Nonreductive physicalism gives an explanation for my capacity for emotion, morality and spirituality, without recourse to body-soul dualism. It goes beyond the idea of ‘bottom-up’ causation of my actions (or reductionism), to include downward causation, so I cannot be reduced to brain damage alone: my higher level capacities are dependent on lower level processes, yet also causative in their own right, emerging from complex interactions of the entire brain. Complex patterns of interaction with the environment have effects on the developing brain in ‘a dynamic interplay between neurobiology and environment’ (Murphy, 2006, p. 101), which includes evaluating cognitive processes in a process that Murphy calls ‘self-transcendence’ (p. 89). The neural complexity involved gives me moral capacity (Murphy, 2006, p. 91). Similar to Damasio’s (2010) ideas of a dynamic relationship between my deeply embedded proto-self and the environment, resulting in a core self (p. 23), nonreductive physicalism can account for a continuing sense of embodied self in dementia.

Dementia is a complex interaction between neurological impairment and social interaction, and is as ‘much a relational disability as it is a physical or neurological one’ (Swinton, 2011, p. 177). I cannot lose my membership of humanity simply by losing my neurones (Swinton, 2012, p. 162). Being in relationships is an integral part of being human: ‘Human existence...is always lived out within human community...To be a person is to be a member of the human race’ (Swinton, 2012, p. 156).

The psychologist Warren Brown’s (1998) view is that we have six enhanced capacities ‘critical for personal relatedness’ (pp. 103–104; my emphasis): language, theory of mind, episodic memory, conscious top-down agency, future orientation and emotional modulation. Brown’s (1998) view that language is essential in relationships, to convey complex ideas and concepts of the past and future (p. 103), could exclude all people with communication difficulties, including those with dementia. I dispute this, as I can still relate to others, despite occasionally having to communicate nonverbally due to words failing me. In this regard, I consider that unlike many other observers, Sabat makes a significant contribution
towards seeing the world through our eyes, despite communication problems. He is an 
expert in listening directly to the voice of people with dementia, conceiving of ‘mind,’ or 
what I regard as self, as a process arising in discourse, akin to an internal conversation 
(Sabat, 2001, p. 222); this is what I call the embodied relational self. Sabat understands how 
communication difficulties form a barrier to meaningful relationships, and how I can feel 
imprisoned behind the barrier of language difficulties and recall dysfunction, yet I am still 
here as an embodied relational self. Indeed, Swinton writes of the possibility that dementia 
‘locks people in’ behind cognitive incapacity, and reflects on whether spirituality might be 
the key to unlock the person ‘in the stillness of that spiritual moment’ (2011, p. 181). 

I have personal thoughts, ideas, images and concepts, which I might have difficulties 
expressing, due to word-finding problems, yet this is only one part of communication. We all 
communicate non-verbally, relying on others to see, as well as hear, what we are saying. In 
my talks, I say, ‘listen with your eyes’ to suggest that caregivers should watch for this 
expressive form of communication (Bryden, 2015b, p. 215).

Theory of mind is the ability to attribute mental states to others, and to have an aware-
ness of one’s own mental state. It suggests that in order to communicate effectively, humans 
need to be able to read the body language and intentions of others. I argue that people with 
dementia may retain such a view of self in the form of imagery, and remain sensitive not to 
the words you use, but how you say them.

Brown (1998) writes of metacognition, or ‘thinking about thinking’ and makes assump-
tions that this ability is gradually lost in people with dementia, despite their lifetime of 
experiences. However, intact social cognition is found amongst people with dementia 
(Sabat & Gladstone, 2010, p. 74). There appears to be a social cognition reserve in 
adults, developed over the course of their lives.

I question Brown’s proposal that episodic memory is vital to relating to others. Why 
should a recall of an historical record of my life and that of others be essential in relation-
ships? Although I cannot recall my recent history, nor a friend’s name or her history, I can 
still relate to her: it feels as if I cannot recall her label, or what is attached to this label. 
However, I can still connect deeply moment to moment, and my relationships are an impor-
tant aspect of my sense of self.

Top-down agency is the ability to regulate behaviour in regard to conscious thought, as 
well as intentions. An example of the retention of these capacities in people with dementia is 
the study by McFadden, Ingram, and Baldauf (2000), which demonstrates that elderly 
residents were active agents, engaging with their environments, with staff, and with one 
another. They showed a wide range of emotions, importantly a caring sensitivity for one 
another. Sabat and Lee (2011) also observed social interactions in which there were inter-
personal understandings amongst people with dementia, based on regulating behaviour 
appropriately.

I cannot envisage future scenarios, nor do I have reliable emotional modulation, both of 
which Brown (1998) regards as vital to relatedness (pp. 103–104). However, I can listen to 
such scenarios, and reflect the feelings I am hearing. I am able to be present in the moment, 
and attend to feelings and emotions. Such reflective listening is a vital aspect for all of our 
relationships, and indeed forms the basis of successful counselling. My capacity to do this 
has not been diminished.

Narrativity is described as a ‘human-forming, meaning-making enterprise’ (Green, 2008, 
p. 121), and as being ‘part of our survival toolkit’ (Bryan, 2016, p. 53). I continue to be a 
narrative self (which I define as my sense of being able to find meaning in life and develop
a sense of narrative identity in the present moment) who is able to find meaning in the present moment. Despite the lack of a remembered precise chronological record, I have ‘a concept of self whose unity resides in the unity of a narrative which links birth to life to death as narrative beginning to middle to end’ (MacIntyre, 1981, p. 91).

Despite recall dysfunction, an unreliable sense of time, and language difficulties, I still have a coherent narrative. The common view that a recall dysfunction means loss of self, and thereby no longer having a meaningful narrative, can be traced back to Plato and Aristotle, who had a simple view of recall as being similar to modern data storage and retrieval (Keck, 1996, p. 64).

Baldwin and Estey (2015) suggest that I must be able to sequence events in time in order to create meaning, and thus a remembered chronology is vital to having and being a story (p. 216). This assumes that my own narrative is reliant on having an accurate recall of events on my time line, but without help, I am unable to recall such events today, or in the past few days, weeks, months, or recent years. However, I can still write this article and reflect on meaning. I do not consider that my remembered history is critical, as I am who I am now, and my meaning is what I can find in this present moment.

Language is not critical for me to be a story, although to share my narrative I will need to be helped to convey this to others. My own experiences and observations of people in the later stages of dementia support Damasio’s (2010) idea of a nonverbal narrative, dependent on the coordination of deep brain structures where the autobiographical ‘self comes to mind in the form of images, relentlessly telling a story of such engagements’ (p. 203).

Indeed, I suggest a robot could be programmed to recall accurately the entire record of its ‘life,’ yet it cannot be regarded to know what it is, or to have a sense of meaning. I question why a lack of a remembered timeline is so important to outsiders, who then regard me as having ‘lost my self.’ My narrative results from finding meaning in life and developing a sense of identity in the present moment, not based on events in the past.

I am still an historical being, who lives in time, and my narrative conveys ‘what it is to live in the world or in worlds, but also what it means to live in time’ (Baars, 2012, p. 150). I continue to be a story in my world: of the relationships and environment around me (Baars, 2012, p. 161) and I agree with Orthodox theologian John Zizoulas (1975) that a ‘capacity for memory is not necessarily a unique characteristic’ of self, nor needed for me to have and be a narrative (pp. 416–417).

**Conclusion**

My published work forms a portfolio of autobiographic narratives, exploring the lived experience of dementia. In this authoethnographic work, I have reflected on a key theme emerging in my work: challenging the concept of a loss of self in dementia. I offer a unique insider’s perspective, of people with dementia having a continuing sense of being an embodied relational self, with a narrative of meaning in the present moment.

I propose three aspects of a sense of self that continue throughout the lived experience of dementia:

*Embodied self:* an aspect of my self that gives me my sense of being embodied as an ‘I’ with first-person feelings about the world around me, distinguishing self from non-self;

*Relational self:* an aspect of my self that gives me my sense of being an embodied self in relationships with God and with others; and
Narrative self: an aspect of my self that is able to find meaning in life and develop a sense of narrative identity in the present moment.

I may be less able to be defined by my doing, but I will always remain an intact being, who needs to belong, to be related to, and to be included. We are all embodied selves who relate to one another as an ‘I’ and recognise an ‘I’. I cannot lose my membership of humanity simply by losing my neurones. My embodied relational self is a way of being, not doing. I continue to be a narrative self who is able to find meaning in the present moment, despite the lack of a remembered precise chronological record. I am who I am now, and my meaning is what I can find in this present moment, which is filled with many aspects of my life, despite needing help to recall these. Within this abundance, my sense of self can continue to flourish.

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References


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