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## CLINICAL PSYCHOLOGY & NEUROPSYCHOLOGY | SHORT COMMUNICATION

# A reflection on the complexity of the self in severe dementia

Amee Baird<sup>1\*</sup>

**Abstract:** What is the impact of dementia on your sense of self? This is a complex question given the various definitions of the self and difficulties in measuring it, particularly in this population. It has been argued that the gradual decline in memory (in particular autobiographical recall) abilities that is associated with Alzheimer's Dementia coincides with a diminishing and eventual "loss" of self. These "memory centric" theories, however, fail to consider other aspects of self that can be relatively preserved in the face of dementia, such as the "interpersonal" and "moral" self. This paper describes the case of David, a surgeon with severe Alzheimer's Dementia, and reflects on the relative sparing and impairment of different aspects of his self, based on his wife's account and the author's interaction with him during a neuropsychological assessment. Drawing on the model of 5 selves proposed by Neisser in 1988, and current literature on the self in dementia, this case demonstrates that our "selves" are not entirely dependent on autobiographical memory, and are not simultaneously "lost" in the severe stage of dementia.



Amee Baird

### ABOUT THE AUTHOR

Dr Amee Baird completed a PhD and Master of Clinical Neuropsychology at the University of Melbourne. She has worked as a clinical neuropsychologist for over 15 years in both clinical and research positions including at the National Hospital for Neurology and Neurosurgery in London, Salpetriere Hospital in Paris, and currently in private practice in Newcastle, Australia. She is currently funded by a National Health & Medical Research Council/Australian Research Council Dementia Research Development Fellowship, and is investigating the relationship between music, memory and the self in people with dementia, in collaboration with William F. Thompson at Macquarie University. This paper describes a patient she saw in her clinical practice which inspired her to reflect on the relationship between autobiographical memory and the self in people with dementia. She is currently undertaking a larger study of this issue with collaborators from philosophy and cognitive science and exploring how people perceive the impact of dementia on the self when considering themselves or others.

### PUBLIC INTEREST STATEMENT

What happens to your sense of self if you develop dementia? This is a complex question as there are different ways to define and measure the self. It has been argued that impaired memory functions in people with Alzheimer's Dementia (AD), in particular difficulty recalling autobiographical or personal memories, causes a "loss" of self. Nevertheless, there are some aspects of the self, such as the "interpersonal" self, or our ability to engage and interact with others, that can remain intact even in the severe stage of dementia. In this paper I describe the case of a surgeon with severe AD who showed some intact aspects of self, based on his wife's report and my interaction with him during a neuropsychological assessment. I propose that our selves are not entirely dependent on our autobiographical memory and that rather than a complete "loss of self" in people with severe dementia, there are some aspects of who we are that can remain preserved.

**Subjects: Psychological Science; Neuropsychology; Clinical Neuropsychology; Cognitive Psychology; CognitiveNeuropsychology; Mental Health**

**Keywords: dementia; Alzheimer’s Dementia; self; autobiographical memory**

What happens to our sense of self if we develop dementia? This question is highly relevant given our ageing population and the corresponding increase in the incidence of dementia. Our sense of self is widely regarded to be informed by our autobiographical memories, and our recognition and understanding of significant people in our immediate environment. It is therefore assumed that if we have difficulty retrieving our autobiographical memories and misidentify or fail to recognise our loved ones in the context of dementia, then our sense of self may be “lost”, or at the very least, unsettled.

In their review of the qualitative and quantitative methods used to study the self in dementia, Caddell and Clare (2010) identified that research on this topic has been challenged by two interrelated issues; (1) the numerous definitions and models of the self that exist within and across disciplines, and (2) methodological difficulties in designing measures of the self/selves in this population. Caddell and Clare (2010) stated that it was difficult to form firm conclusions due to methodological variations between investigations which addressed different components of the self and reflected various models and concepts of self. The majority of qualitative studies were cases or small samples and typically demonstrated that the self was preserved, while the quantitative studies suggested that some components deteriorated as the disease progressed. They highlighted the need for further studies to be based on the development of measures to assess various aspects of the self, and a clear theoretical framework of the self, and suggested Neisser’s (1988) model as most appropriate.

This model proposed 5 selves;

- (1) ecological self, or the self as it is directly perceived (through processing of sensory information) with respect to the physical environment. In other words, the position and movements of our bodies in the environment.
- (2) interpersonal self, or the self engaged in personal interactions (two or more people).
- (3) extended self, or the self as it was in the past and what we expect it to be in the future, primarily based on memory.
- (4) private self, or personal experiences that are not available to others, such as dreams and beliefs.
- (5) conceptual self, or self concept—a concept of oneself as a particular person, for example, social roles and social/cultural differences.

Neisser stated that these “selves are not generally experienced as separate and distinct, because there is stimulus information to specify their cohesion. In cases where such information is less salient, the unity of the self is correspondingly weakened. But unified or not, all five ‘selves’ are of fundamental importance” (1988, p. 36).

Gallagher (2013) extended Neisser’s model in his “pattern theory of self”. He proposed that a self is a “cluster concept” that includes a number of characteristic features, such as affective, psychological/cognitive, extended (physical objects) and situated (environmental) aspects, organised in certain patterns. In reference to Alzheimer’s Dementia (AD), Gallagher argued that despite reduced ability to recall one’s past, self-identity may continue to be supported by other aspects of the self, such as intersubjective relations. “This is not to say that such changes do not result in a modulation of self-experience or self-identity, but rather, since self is not reducible to any one of these aspects, it is a modulation rather than a complete loss...if someone lacks memory...she continues as a self if there are a sufficient number of aspects still intact” (Gallagher, 2013, p. 4).

This notion challenges the widely held assumption that autobiographical memory is a necessary requirement for a sense of self, and that a decline in our ability to retrieve personal memories results in a corresponding “loss of self”. The complex relationship between autobiographical memory and the self in the context of AD has been addressed by several authors (e.g., El Haj, Antoine, Nandrino, & Kapogiannis, 2015; Mograbi, Brown, & Morris, 2009; Tippett, Prebble, & Addis, 2018). Theories range from those that consider that a decline in the ability to recall autobiographical memories corresponds with a diminished sense of self (El Haj et al., 2015), or a failure to update self-knowledge resulting in a static, outdated self concept (Klein, Cosmides, & Costabile, 2003) or a “petrified” self (Mograbi et al., 2009), to a more multifaceted notion that the integrity of narrative construction from semantic memory underpins the sophistication and certainty in beliefs about self persistence over time (“diachronic unity”, Tippett et al., 2018). Overall, these “memory centric” models have articulated how the self can be disrupted by the deterioration of autobiographical memory. They fail to consider the importance of other “non-memory” aspects of self, such as extended (physical objects) and situated (environmental) factors. Different aspects of self can be activated and enhanced by environmental triggers, such as familiar objects, photographs or music (Baird & Thompson, 2018). There is also evidence that moral traits are considered to be the most essential part of the self, and various types of memory abilities are considered less important. In a series of online survey studies that involved people rating perceived change in self/identity of characters in hypothetical scenarios (Strohming & Nichols, 2014) and carers’ ratings of how much people with various types of dementia were still the same person (Strohming & Nichols, 2015), the “essential moral self hypothesis” was supported in that morality was considered the most central part of the self, with only modest importance placed on personality, memories and desires. The types of memories that were considered most relevant to self were those involving social relationships.

I reflected on these issues of who we are in the context of dementia during my meeting with David, a retired surgeon, who I saw for a neuropsychological assessment. David’s typical response to my questions was “I don’t know. You got me” or “I can’t think. What was the question? My wife will know”. When I asked about his mood he replied, “What’s the choice?” He denied feeling sad, and when prompted with “Do you feel OK in yourself?” he answered, “I suppose so”. He often asked, “What do I have to do?” half way through a cognitive task. He was intermittently agitated, particularly during tasks that he found challenging, and made comments such as “These are not sensible things to me” and “I don’t like doing these tricks. Let’s just leave it at that.”

David’s difficulty in recalling aspects of his history is in keeping with the known decline in autobiographical memory in this population. His inability to describe his mood suggested that he had difficulty with self-reflection. Nevertheless, his dismissal of the cognitive tasks as “tricks” that were “not sensible to him” could be interpreted as a form of self-protection, which suggests preservation of some form of self. According to his wife, however, there has been a dramatic loss of self, or at least of the self that she knew: “There is none of him left. We’ve been married 54 years and it’s like living with a stranger”. This suggests that the “ecological” (Neisser, 1988) or “embodied” self, or the notion of a pre-reflective sense of agency that manifests in corporeal ways (Kontos, 2004) is not sufficient for others, in particular spouses, to view one as an intact “self” in the context of severe dementia. Given the increasing dependence on others in the face of any type of dementia, it is likely that that our “social” or “interpersonal” self (Neisser, 1988) is crucial. I wondered what features of the self or selves need to remain preserved in order for others, in particular loved ones, to feel that the self they knew remains. Lindemann (2009) proposed that other people, particularly family members, and even familiar objects, can “hold a person with dementia in their identity”. I wondered how David would react to seeing and holding his old stethoscope or scalpel, and if these significant and highly familiar objects would restore him, even briefly, to the self that he inhabited during his long surgical career.

A successful surgeon who had graduated from medical school as one of the top students, David’s declining cognition must have been a significant threat to his sense of self (Clare, 2003). I imagined him striding along the hospital corridors with supreme self-confidence and authority. It was a striking contrast to the frail man that clutched my arm and repeatedly asked, “Where are we going?” on our way to my office. His cognitive decline was also a challenge for his wife and she spoke candidly of her

slow adjustment to it. She commented, “He was always much smarter than me. I used to use his brain as my brain”. I thought of how their relative roles in their collaborative memory waltz had completely reversed, with his repeated response of “my wife will know”. Given his medical background she never attended any medical appointments with him. It took several years before his cognitive decline was investigated, as she initially attributed his forgetfulness to his hearing difficulties. He was already in the severe stage of dementia at the time of my assessment.

During our farewell, he suddenly appeared more confident and thanked me for my time, and his handshake was remarkably firm, his “embodied” and “interpersonal” self guiding him through this well rehearsed gesture. His wife said, “He has his lucid moments”. She recently asked him when they were going out, “Have you got everything you want?” He responded, “Yes, except my brain”. This is not a comment made by a man who has lost himself entirely, or one who has a “petrified self” with a failure to update self knowledge (Mograbi et al., 2009). In stating that he does not have his brain, he is clearly aware that he is not who he was. It raises the question of whether it reflects a new self with dementia realising that he is different from who he was pre-dementia, or whether it represents a modified version of the self he always was, recognising that something is missing. It demonstrates the integrity of his “private” and “extended” selves, and an altered “conceptual” self (Neisser, 1988). Specifically, his private self is aware of his cognitive difficulties, and his “extended self” has reflected on the difference between his current and past cognitive abilities. The comment also implies a change in his “conceptual self”, to a person who is “missing” his brain.

I spoke to his wife 6 months later, by which time David was residing in an aged-care facility. She recently took him for a drive to the holiday unit they had owned for 20 years, but he did not recognise it and could not find his way around. She recalled a conversation they had while there, when he asked how his brother was. He had to be reminded again that he had died, his grief as raw as the first time he heard this devastating news. He enquired about his sister-in-law, and was happy to hear she was coping, responding, “Oh good, she has her life back”. After a few minutes silence he asked, “And what about you?” His wife admitted she was less stressed now he was in the nursing home, and he replied, “Thank goodness, *but don’t forget to live*”. She felt this comment revealed a glimpse of his “empathic” self bursting through his dementia fog. She told me “His core of kindness and caring is still evident”. Empathy may be considered part of an “essential moral self” (Strohmingher & Nichols, 2014, 2015), and his comment demonstrated that this trait was still evident, and he was still there, despite his severe dementia.

David convinced me that there is more than one self, and that our selves are not entirely dependent on autobiographical memory, and are not simultaneously “lost” in the severe stage of dementia. The question of whether a new self or selves can manifest, or old selves are adjusted, remains.

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#### Disclosure of interest

The author declares no conflict of interest.

#### Competing interests

The authors declare no competing interests.

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#### Ethical statement

David’s wife (as his legal authorised representative) provided written informed consent to publish this case.

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