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The Self in Dementia

Sylva Sarafidou

Department of Neurology and Psychology, Ideas, Center of Psychology, Neuroscience, Art, Greece

*Correspondence to: Dr. Sylva Sarafidou, Department of Neurology and Psychology, Ideas, Center of Psychology, Neuroscience, Art, Greece.

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Abstract

The self is a highly abstract construct, challenging to address in research. The self within dementia tended to be perceived as 'gone' due to the nature of the disorder. This though is problematic both theoretically and practically. There are both theoretical and experimental data that indicate the existence of the self, throughout the course of neurodegenerative disorders, fact which raises several important implications. The self should be targeted in the psychosocial treatment of dementia because it could benefit the person from a neuroscientific and a psychotherapeutic point of view. This can be achieved through a focus in all aspects of the self throughout time (somatosensory, cognitive, emotional, behavioural and social), and in the 'here and now' of the person. Preliminary data indicate that targeting the self could lead to delaying the progression of the disorder, and overall, improving life quality. More research is required to arrive to solid conclusions.

Introduction

The concepts 'self' and 'dementia' seem to have an odd relation. The self as a term implies the cognition and metacognition, both of which are gradually impaired in cases of neurodegeneration. Yet can the self be seen

as 'absent' in the dementias? The self-perceived as 'gone' is questionable, whereas there are evidence towards its existence, fact which raises several implications. A focus on the self in the psychosocial treatment of dementia could benefit the person, and could be achieved through targeting all the aspects of the individual separate and combined as they are exhibited throughout time and in the 'here and now'.

The Self as 'Absent'

In the past it was widely accepted that as dementia progresses, the self is fading away, until it is entirely lost in the latest stages. In a way, it makes sense: the person cannot recall autobiographical memories and information, the personality seems different, and interpersonal relations diminish [1]. Is that person still 'himself'?

Still, accepting that the self is 'gone' in neurodegenerative disorders appears problematic. In the theoretical sphere, if the self is gone, what is 'left'? As Millet states, an 'ontological nulpoint' is reached- where the individual is a 'non- person' by default. The person continues to exist within an environment and interact with it in unique ways, no matter how severe the neurodegeneration- a 'non- person' is not capable of interacting with the world (2011). In the practical sphere, professional caring and treatment can become impersonal and lack respect, since a 'non- person' has no dignity to be preserved through them. A 'non- person' does not have the same human rights (not only in caring but in general) as a person. Similarly, caregiving by family members can become a burden, since the caregiver offers to an individual, who is no longer the person they knew. In fact it is common for caregivers to experience grief while the person is still alive, since they perceive that the self of their loved one has disappeared [2].

We tend to perceive the self as gone when we link it only with cognitive abilities and metacognitive skills, such as autobiographical memory or consciousness [3]. But the self is not a simple construct, it is a complex and unique entity! It has a cognitive aspect, but also an emotional one, a behavioural, a social one, and a physical one. The combination of all these aspects create the unique set that each person's self is (Woods, 2001) [4]. Reducing a person to cognition alone could lead us to believe that the self is gone in cases of progressive neurodegeneration, but upon perceiving the person as an actively existing agent with a unique sum of characteristics, the self can be detected even in severe dementia [5].

The Self as 'Present'

The existence of the self is apparent in several ways. The definition of the term alone implies a dynamic entity, capable of incorporating the changes of time and environment [6]. In fact, even in cases without dementia, the self-changes with time and experience: one is not the same person at age ten and again at age thirty. The self can adapt to the needs, and capabilities of each phase of the person's life, thus it is could be deducted that it can readjust to dementia (or any other condition) as well.

Extending this argument to the neuroscientific sphere, the self can be 'found' in all the parts of the brain, and can be exhibited from frontal lobe, complex skills (such as self-perception) to more basic and instinctual temporal lobe abilities (such as primary emotions) [3]. This would imply that although some parts of the self may be influenced by the disorder (as the respective parts of the brain are damaged), yet some part of the self (and brain) suffer little to no damage, fact which indicates that the self is maintained.

Moreover, individuals with dementia, even in the latest stages, exhibit different cognitive abilities, emotions and behaviours, all of which are manifested in entirely different ways, fact which is an indication of the uniqueness of the self [7].

In the experimental field, the self has manifested itself through several researches. Some have undertaken a quantitative approach, aiming at detecting the self with questionnaires answered by the individual, tailored for the needs of the population [8,9]. Similarly, in other studies the self has been investigated qualitatively through structured interviews with the person [2,10]. According to the findings of these studies, the self is maintained in dementia, despite the cognitive decline. More specifically, it has been found that the cognitive aspect is reflected in the performance of the individuals (thus the cognitive level and the level of progression of the disorder do play a role) yet the essence of the self is 'still there'. Another set of studies has investigated the self in dementia by proxy- through questionnaires with the formal (health care professionals) and informal (family) caregivers of the individuals. Finding here are mixed, since some studies argued that the self is maintained, while others that it is not, due to the cognitive symptomatology [1,11]. To sum up, the majority of studies have concluded that the self is maintained in AD, and that it can be experimentally detected.

Overall, according to research, individuals with dementia can define themselves, exhibit self-properties (such as self-esteem, self-knowledge, self-care, etc), and interact with their surroundings in unique ways throughout the course of the disorder [3].

Implications of the 'Present Self'

Accepting the existence of a self within dementia has many theoretical and practical implications. In the theoretical sphere, the self can be considered along with neurological and psychiatric conditions, and not in opposition to them. The self may be influenced by the neuropsychiatric condition but it is not reduced solely to it. As mentioned above, the self can incorporate the changes of the condition, but not be defined only by it. Most of all, individuals who have a 'self' have human rights, thus deserve a fundamentally moral treatment, and a humanitarian behaviour, even if they cannot claim it for themselves [6].

This leads to the practical sphere, where caring is altered radically by the belief in the existence of a self: moral care, promoting dignity, respect, and an individualized approach and treatment to the person. Professional caregivers can find meaning in working with individuals with dementia, instead of perceiving their jobs and efforts as pointless. Similarly, family caregivers can find meaning in offering to the person instead of hopelessness [7].

Most of all, accepting that the self is maintained in dementia can lead to improved outcomes for the person: both caring and treatment become more effective. In fact, an important line of preliminary data has indicated that the existence of the self, and a focus on it may be linked with improved life quality, fact which make the self an intriguing treatment target [3].

The Self in Psychosocial Treatment

Focusing on the self and all its aspects in the psychosocial treatment of dementia can be achieved through targeting all aspects of the person (somatosensory, cognitive, emotional, behavioural, social) separately but also as a whole, and all aspects that the disorder influences. It is a holistic approach to treatment, incorporating efficient elements from both psychotherapy and neuroscience, and the goal is to improve the life of the person- through this focus on the self.

The construct though is highly abstract and challenging to target practically. The first step is to focus in all the different aspects of the self, without neglecting one in the face of dementia [4]. The person has thoughts, feelings, behaviours, relations with the world around, personality characteristics, preferences, and many more, all of which are brought to the surface. The professional can ask about them, or 'remind' them to the person. More specifically, the somatosensory aspect is engaged through sensory activation techniques (such as sensory activates or coordinated movement), the cognitive aspect is enhanced with cognitive reinforcement techniques (such as verbal exercises), the emotional aspect is enhanced through promoting genuine emotional expression (with open- ended questions and active listening), and the behavioural aspect is targeted through behavioural adjustment (with behavioural techniques or socializing). All these aspects are targeted separately yet all are combined and linked to the self and its qualities (such as self-knowledge, self-care, self-blame, etc).

The second step is to focus on the self within time. Bring characteristics and events of the past to the foreground, link them to the present state of the person, and the potential future one (for example discuss how the children of the person have grown up, had children of their own, and how the person may see their grandchildren grow) [7]. Through these the self is manifested as a cohesive whole throughout time, even if this is challenging for the person alone, due to cognitive symptomatology.

The third step is to extend the focus in the 'here and now'. This is twofold: on the one hand, there should be a focus on the existing skills of the person, instead of the ones that are already heavily impaired [12]. This would be a hopeless goal, thus professionals can work with the abilities that are still functional and re-structure the everyday life of the person based on them. On the other hand, there should be a focus in the needs of the person in the present. What are the thoughts, emotions, behaviours and needs of the person within each moment? An individual with dementia has several different and growing needs all of which can be addressed through moment- to- moment adapting. This will allow the person to exist within the environment as functional as possible [7].

All these steps can lead to several benefits for the person. From a neuroscientific point of view, several brain structures and functions are activated in each interaction (or session) through the multidimensional engagement [13]. Thus, the disorder is delayed as much as possible, and the person remains as functional as possible for as long as possible. From a psychotherapeutic perspective, the person is active and engage in their treatment, which is tailored to their particular needs and preferences (both at each moment and from a broader view). Thus, the person can find meaning in living (with dementia), and can experience an improvement in the overall quality of life [7].

Focusing on the self therapeutically may seem as not a necessary primary goal for dementia, yet it incorporates somatosensory and cognitive reinforcement, emotional expression and behavioural competency [5]. Therefore a focus on the self-targets all aspects of the person and all domains that the disorder influences, making it a holistic and practical treatment goal.

Conclusion

The self in dementia has not attracted a lot of research attention, and much more data is required in order to arrive to solid conclusions. Preliminary findings indicate that the self is maintained even in cases of severe dementia, and the person is highly benefited by a therapeutic focus on the self, throughout the course of dementia. Hopefully, more research in the experimental and clinical field will be able to deal more scientifically with the abstract construct that the self is.

Aknowledgements

The current paper had no conflicts of interest.

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