



RESEARCH ARTICLE

NEURODEGENERATION AND THE SELF: A CASE STUDY WITH IMPLICATIONS FOR THERAPY

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ABSTRACT

The self is a highly abstract construct, challenging to assess through research, especially in neurodegenerative disorders. Still, there is a great need to understand whether the self persists in disorders that affect the structure and function of the brain, since either conclusion would have important implications for brain function, for the theoretical approach to the self, and the experimental and clinical focus on it. How can we assess the self in cases of progressive neurodegeneration? Why is that important? A case study of a man with progressive multifocal encephalopathy, which developed into dementia, is presented. Most roots of communication (with others and with the environment) were influenced by the condition, yet the self made its appearance through cognitions, behaviors and emotional reactions. Using all aspects of the self as a stimulus, the person was able to connect to his surroundings, and develop a therapeutic alliance with the therapist, which was evident through behavioral and emotional expressions. This, in turn, allowed him to find meaning in the experience of living with a progressive disorder and become more receptive and active in the process of the treatment. The self is present even in states of high neurodegeneration, and it can be targeted therapeutically in order to connect the person with the 'here and now'. There is a great need for accurate assessment and in- depth understanding of the subject, as well as for further research in the field. The case study brings forth several theoretical implications (concerning the self within a degenerating brain), and has a variety clinical applications, while the need for a psychosocial intervention in the progressed stages of dementia is made apparent.

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INTRODUCTION

The 'self' as a concept has attracted the attention of religious thinkers, philosophers, scientists and individuals almost since the dawn of time and civilization. Many have struggled to define the term and understand it, ranging from Gautama Buddha and Plato, Descartes and Hume, to the modern psychoanalysts and neurocognitive scientists (Leary, Tangney, 2012). Similarly, dementia (and the neurodegenerative processes that come with it) is a condition almost as old as mankind. Philosophers and legal thinkers, such as Plato, Solon, Galen, have recognized that old age was often accompanied with memory and judgement problems (Boller, Forbes, 1998). The two concepts, self and neurodegeneration, have an odd relation. The self is often perceived as 'lost' in cases of progressive or severe neurodegeneration. Both in research and in the clinical practice it used to be widely accepted that the self diminishes along with the progression of the symptomatology, until it is entirely 'gone' in the latest stages.

This though appears problematic both theoretically and practically. In the theoretical understanding of the self, if the person is perceived as having lost the self, what is 'left'? Can there be a person without a self? This leads to an 'ontological nullpoint' where the person is perceived as a 'non- person'-fact which brings us to a theoretical dead- end (Millet, 2011, 509). Moreover, the self is considered as 'gone' when it is represented through cognitive and metacognitive abilities (such as self- referencing skills); would that imply that the self is a cognitive construct? In researches that have defined and assessed the existence of a sense of self in cases of dementia through the lens of cognition and metacognition, it appears that the self is highly influenced in dementia: it has been argued that it is impaired, especially the social aspect of it (Fargeau, Gil, Houeto, Jaafari, Pluchon, Ragot, 2010). To take this a step further, that should indicate that the self can be located into specific functions and structures of the brain. Much research (especially through the use of neuroimaging techniques) has linked the self with the prefrontal cortex and its functions, and some research has indicated that specifically the medial prefrontal cortex (MPFC) is highly relevant, but the conclusions are so far complex and incomplete (Beer, 2012). In the practical aspect, if the self is considered as 'gone' then

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formal and informal caring for individuals suffering from neurodegeneration could lack respect for the person, and could deprive the individual of their agency, dignity, quality of life and of care (Hadjistavropoulos, Hunter, Kaasalainen, Malloy, Smythe, Williams, 2013). Overall the view that the self is 'gone' in cases of neurodegeneration is problematic, lacks the support of strong evidence, and could lead to demoralized care. To fill the gap in the literature some recent research has aimed at investigating the self in cases of dementia. It has been recently argued that individuals with dementia maintain a sense of self, despite the neurodegenerative disorder. There is both theoretical and empirical support for the argument. Theoretically, the self was usually assessed through cognitive skills (such as autobiographical memory) or metacognitive abilities (such as the ability to reflect on the self) (Leary, Tangney, 2012). Yet it can be perceived as a dynamic and multifaceted construct.

The dynamic property of the self allows the person to change based on the abilities and needs of each age, yet remain the same inside, have a 'stable core' (Millet, 2011). The many aspects of the self could be seen through: the cognitive abilities and cognitions linked with it (such as self- knowledge, self-regulation, self- awareness), the range of emotional experience, expression, and motivation (such as self- relevant emotions, emotional reactions based on the self, self- conscious emotions, self motives- like the motive for self- enhancement), the behavioral and social experience and skills (such as self-control, the self as a 'doer', behavioral expressions of the self through personality, the social self), the self- related constructs and phenomena (such as personality, identity, self-actualization, self- esteem), and through the physical and sensory reality of the person (Leary, Tangney, 2012). To combine, the self has a cognitive, a behavioral, an emotional and a physical aspect (Woods, 2001). Linking with dementia, parts of these aspects are influenced by the neurodegeneration, but not all of them- thus a core of the self remains, even if it is altered due to the condition. Moreover, the person continues to interact with, and influence his/ her surroundings, fact which make the individual an active agent, even in cases of severe brain damage (Millet, 2011). Empirical evidence support this argument. Studies have shown that the self appears almost unharmed in the first stages of dementia, with the many aspects of it remaining similar to the past (Clare, et al, 2012) Other studies have shown that in cases of early- onset dementia the self may be altered but, again, aspects of identity remain 'there' (Harris, Keady, 2009). Finally, when it comes to advanced dementia (and specifically Alzheimer's), it has been argued that the self exists and can be detected (Desgranges, Eustache, Eustache, Juskenaitė, Laisney, Letortu, Platel, 2013). Moreover, neuroscientific studies have indicated that self-related processes and aspects are located in different parts of the brain, and of the prefrontal cortex, making the sum of the self relying on several brain structures, thus more enduring to brain damage. Other neuroimaging studies have shown that referring to the self may cause higher stimulation of the MPFC, compared to referring to others, or information non related to the self (Beer, 2012). Taken together, neuroscientific and psychosocial findings indicate that the self may persist and endure throughout the process of a neurodegenerative disorder. The existence of the self in cases of severe neurodegeneration was manifested in the case study of X.

Case Study: X was a man of 48- he was healthy physically and mentally, until the sudden loss of a parent, after which he

exhibited certain symptoms. At first (as informed by the caregiver, and his clinical history) he was diagnosed with clinical depression with catatonic symptomatology. Increasingly he developed certain neurological symptoms (such as hardship in the process of writing, typing and expressing himself, which were central to his occupation, slower eye movements), which were initially attributed to depression but which expanded into severe dizziness, and inability/unwillingness to get out of bed even for the basic needs. The symptoms lead to a car accident, which did not cause any serious physiological or brain damage, yet upon waking up his brain function was changed and highly decreased. This state, along with the lack of proper diagnosis at that point, intensified, and the man ended up losing many central brain functions (such as the ability to coordinate movement in order to walk). A little while later the man was assessed by a neurologist, was properly diagnosed with progressive multifocal encephalopathy, and was submitted to an inpatient unit specializing in dementia. At the same time, due to his overall poor health, he developed an infection of the lungs, for which he was treated.

A little while later, he was assigned to me in order to offer a psychosocial intervention. When I met him, he was in a state of severe neurodegeneration. Encephalopathy, a relatively rare condition, is a form of infection of the central nervous system, caused by the papova virus, JC. It leads to changes in the brain structure and function: there are damages in the white matter (as shown through MRIs) and mainly the occipital and parietal regions are affected; 'centers' of infection are progressively created in different substructures of the nervous system- with impairments starting with the more complex (frontal lobe) capabilities, and leading all the way to somatosensory and verbal damage (Fuller, Manford, 2010, Darby, Walsh, 2005). The level of neurodegeneration lead to the exhibition of dementia due to other medical condition, and the symptomatology covered a wide range. In the first meeting with the man, I came across a person who could not move his limbs consciously or stand (he was placed in a chair with arms in order for them to help him not fall over in his side), could not eat (thus was feed through gastrostomy), could not direct his gaze or maintain eye contact, could not control his somatic functions, could hardly verbalize some words. Most of the time he had his eyes closed, was unresponsive to any environmental stimuli (sounds, lights, me talking to him), and only reacted when he experienced a caughing spree (which was often and intense), or when a nurse tried to do something 'disturbing' (such as dressing him, picking him up from bed, feeding him, etc). In an assessment, he scored 0 in the MMSE, and 1 in the Severe version of it, while he was unresponsive to sounds, lights/ darkness, touch, smells, despite the intensity of the stimulus. This unresponsiveness, apathy and detachment from the environment were going on for many of our sessions- I was beginning to feel desperate. It was then that I noticed: in his Severe score he had said his name (hence the score 1), and every time someone said his name he moved his eyes (whether they were closed or open- there was some kind of movement). I tried to assess whether he would be responsive in some way about other information linked to the self, through talking to him. I would ask or state characteristics and qualities of the self, drawing from the information offered by the caregiver (for example about personality traits, preferences, his job). Through that some initial responses were observed: a slight movement of the eyes, or of the hand, a slight kick with the foot- all of which were not occurring when I was talking about things non

related to him. I expanded this 'strategy' by talking about him in the past, present and future, bringing him to the 'here and now', and explaining it- breaking it down for him (for example 'the usual nurse is coming now to give you food, ok? You have your eyes closed, and she may touch you, this should not scare you'). His responses were increasing and sometimes he would open his eyes, and in some rare occasions he would direct his gaze toward me, he would move his limbs intensely- with a slight sense of control. He used to write, so in some occasions I read to him things that he had written. One day I read to him a part from one of his stories- he began to shout, and move his body- he seemed to recognize but dislike what he heard. I asked him 'Who wrote that?' and he said 'Me'. I asked 'Do you like it?', he answered 'No' (and after asking why) 'I can't write now'. At that point I tried to offer cognitive, emotional and physical stimuli related to the self in all our sessions. Referring to his past, and explaining his present appeared to be of help. We progressively began having 'conversations', and he slowly began to exhibit 'trust' towards me. He would say 'hi' and answer if he is well or not when we met (which was a huge progress), he would look at me at least once during each session, he expressed his needs verbally and was ok with certain activities when I was there explaining to him (such as feeding), he reacted emotionally (either negatively through shouting or positively through calmness) and behaviorally (spoke about it, or nodded) to stimuli regarding the self in the past, and was more receptive in stimuli from his present (he did not react aggressively in the daily 'obligations').

What was interesting was that he did not react the same to neutral or false stimuli at different time points. For example when I presented him with incorrect information about himself he was able to state that- for example in the question 'are you a young child?' he would answer 'No', as well as in the question 'are you a doctor?', whereas in the question 'do you like dogs?' he would say 'Yes'. When I read him his own texts, he was somehow reactive (based on the moment), whereas when I read him texts by others he would be unresponsive. Similarly when I spoke of random themes he was indifferent, whereas when I spoke about him or said his name there would be a hint of reaction. Also, information regarding the self could cause an emotional reaction and irrelevant information- even if it had an emotional valence, did not. The man reacted cognitively (through understanding and relating self- knowledge), emotionally (either stated clearly 'I am happy/ sad/ ok', or expressed through facial expressions and physical posture and movement), behaviorally and physically (through moving the body by command, or using the body to direct/ point to something, nodd) in stimuli regarding the self. This is an interesting fact, since at some points he appeared as if some skills were entirely impaired, and at other (brief) times he exhibited use of these skills (such as moving the body willingly, speaking clearly using words, directing the gaze, etc). It seems as if they were inactive, and could be activated through using the self as a stimulus. This in turn brought the person in the 'here and now'. There were many sessions of intensity, where the man 'existed in the present'. In one occasion, I read to him a text of his concerning hope. He began shouting- I asked him to state with words what he wanted. He said 'I am not well. I want to be well.' I told him 'Do you try to get better?' 'No', 'Do you not hope? You wrote here that you hope'. The man's facial expression changed into a face of sorrow, his eyes teared up, his fist clenched. 'I hope' he said, and he cried. Several similar events (with very high emotional intensity) occurred, during which the man could recognize his

current state (said he could not write now, but could in the past), and could come in connection with his surroundings. All these indicate that even in cases of severe neurodegeneration and progressed dementia, the self persists, and finds a way to manifest itself. The current case study indicates cognitive, emotional, behavioral and physical manifestations of the self. Although it is not easy to formally assess the self in such cases, it is possible to detect it through careful (day- to- day) observation. This is important in the psychosocial treatment of neurodegenerative disorders, since in some cases it could be the only way to evoke interaction with the surroundings, and bring forth functional behaviors (as much as possible of course).

DISCUSSION

The case study of X, a man with encephalopathy, indicated that the self is present even in cases of severe neurodegeneration, and it can be a 'useful tool' for treatment. The fact that the self is maintained in cases of progressed dementia is in line with previous research. Individuals with younger- onset dementia (thus closer to age with X) exhibit some sense of self and individuals with advanced Alzheimer's may exhibit changes in their self but a core remains and is detectable (Desgranges, Eustache, Eustache, Juskenaitė, Laisney, Letortu, Platel, 2013, Harris, Keady, 2009). Moreover, it has been argued that parts of the MPFC are activated when referred to the self instead of when referring to others (Beer, 2012). Taken together, psychosocial and neuroscientific evidence indicate that the self is a dynamic construct, able to incorporate change, and it is multifaceted- it can be manifested through different domains, and it can be 'located' into several brain regions. Through these properties, the self can be maintained even in cases of severe neurodegeneration and find ways to 'appear'. Referring to the self could activate several brain regions, thus the self could function as a stimulus in order to cause interaction with the environment, and exhibit the maximum possible level of functionality (Leary, Tangney, 2012). The interaction with the environment on its own is an indication of the persistence of the self as an acting agent, fact which strengthens the argument from a theoretical viewpoint (Millet, 2011). The current conclusions have a great importance. They provide a mean of communication with the surroundings, and allow the person to understand and find meaning in the experience of suffering- at the level that it is possible for each one. Moreover, they allow a 'therapeutic alliance' (a term accustomed to the potentials of each person) to develop, which could be helpful in everyday interactions and can further assist in more communication (Lipinska, 2009). Overall, the case study of X indicates that there is a need for some kind of psychosocial intervention in severe cases of neurodegeneration- even in instances that seem 'helpless' in a first glance. The findings can be applied more widely in clinical settings with individuals with neurodegenerative disorders, who could benefit from private sessions, and to the general style of interaction with these individuals, where the self could be recognized and brought to the surface. Yet the case study had some limitations. Progressive multifocal encephalopathy is a rare condition, with little to no existing literature on the subject of interventions or of the self. Literature was drawn from dementia cases, which is the condition that was ultimately developed here. Still, the causes and effects of the encephalopathy are slightly different from the dementias, fact which complicates the neuroscientific explanation of the findings. A lot more research is required to understand the specific mechanisms that underly this disorder. Moreover, due to the extensive damage, there was no formal

assessment of the self, yet it was observed through many instances. This indicates that it is not always possible or efficient to use standardized measures in the clinical practice, fact which would require a more clear 'qualitative' understanding and detection of such constructs. Still, the current case study generates several implications. The possibility to manifest a 'self', even through moment-by-moment interaction, thus existing as an acting agent implies the 'universality' and endurance of the term. More research is required to better understand the construct as a whole, and be able to efficiently assess it psychologically and neuroscientifically, yet it appears that the self manages to persist (Leary, Tangney, 2012).

The use of the self as a stimulus caused the person to be more present and active in some way, thus made him as much as possible functional; which in turn is important because it led to an improvement in his life quality (since everyday tasks, such as getting fed, or bathed, were conducted with less agitation, and since he began communicating his needs, thus have them covered, such as feeling cold and needing a jacket). The existence of a sense of self has been linked with improved life quality in cases of dementia, but more research is required to address the issue, especially in other disorders (Clare, et al, 2012). An important implication regards brain function: X appeared capable of using certain skills (such as verbalize words) when he was stimulated appropriately, whereas at other times he seemed as having lost such skills; it appears that they were dormant, and were activated through self-related information. This implies that brain function is composed of interconnected processes, and is ready to compensate in novel ways the damage suffered to a great extent (Derby, Walsh, 2005). A lot more research is required to further grasp the complexity of the brain and its capabilities during hardships. A crucial implication concerns misdiagnosis: X was incorrectly diagnosed with depression by a mental health professional, thus his true condition remained untreated until it had progressed a lot. Professionals should be aware of the potential of a misdiagnosis, especially in cases of more rare conditions, and be ready to refer to others, or examine more thoroughly. The most important implications regard the psychosocial approach to neurodegeneration. Often there are no obvious roots of communication with a person suffering from severe brain damage, yet this should make us 'give up' on them. Even in cases of late stage dementia there are ways to help the person through an intervention, tailored to their particular needs (Parks, Williams, Zec, 1993). The person can relate to others in some way; even in such cases and disorders, the 'therapeutic alliance' can still be our most important tool. Still, and importantly, working with individuals with degenerative disorders, along with the emotional intensity that often comes along, could burden the therapist psychologically in the long run; therapists could find ways of compensating for that, such as supervision (Lipinska, 2009). All these in turn, imply that the fields of psychology and neuroscience could become more flexible and think 'out of the box' in assessing and treating neurodegenerative disorders, and abstract constructs- again more research is required to develop efficient interventions with individualized elements, and understand more clearly the mechanisms underlying the disorders, and the self within them.

Conclusion

The case study of X was a highly intense experience, with great variation within it. Intense emotions and excessive behavioral

expressions were interchanged with apathy and unresponsiveness. The 'take-home' message would be to keep in mind that there are hidden capabilities within each person- in the first meeting with X I noticed all he could not do, throughout the process of treatment though there was a focus in discovering all the things he could still do: have needs, experiencing emotions (fear, sorrow, joy), relating to others, remaining himself, while his brain was fading away.

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