

Dementia: A Body without Brain (Cognitive Abilities)

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ABSTRACT

Dementia is like social death before the actual death; a paradoxical life that does not allow one to live life as they used to live before the affliction. It is such an evasive and pervasive disease that the impact it would have on the life of people is unimaginable. This condition flares up the eternal quest of mankind; whether the brain is greater than the body or vice versa? The person suffering from dementia becomes a sort of illusionary lost being lost in the incoherent, insensible, unexplored ethos of his own mental web and can no longer associate or participate with the environment.

In trying to understand dementia, the researcher has looked at a number of issues surrounding the interplay of the body, the mind, and personhood. What does it mean to be a person without the sharpness of mind or the collective experience of his memories or a personality that is built upon the basis of cultural and historical context? Would this person be the same one as before without the sum of these things? Is society accommodative of people with dementia? Is there the same sort of support structure around this disease of the mind as there is for many other physical ailments? Is the existence of humankind totally defined by cerebral power and is a person completely destroyed when the brain cannot sustain psychological connectivity? Would there be any meaning attached to a demented person's existence if his existence is embedded in his life history, engagement with others, and his bodily forms? Through this paper, the researcher has tried to look at these questions from the point of view of the demented protagonist in the novel *Still Alice* by Lisa Genova and how these tragic and painful experiences are accommodated by society at large.

Keywords: Cognitive abilities, personhood, mental health, psychological connectivity, culture, dementia.

Beckham (2008) draws a similarity between dementia and monster: Dementia is a monster knocking at the door like an unwelcome guest. One cannot tame it, outrun or outwit it but only fall like a helpless victim in his hands ready to be gulped down, as there is no place where the victim can run and hide. All these comments illustrate that dementia is a kind of tragedy without a single sigh of relief in it. It is the most feared disease of our times, questioning all the medical advancements of the modern age because no cure has been discovered to treat it.

Dementia is a disease of the brain, in which the cognitive abilities, memories, and mental capacities of the person decline gradually. Memory loss that disturbs daily routine, difficulties in managing daily household chores, no recollection of words while writing or speaking, misplacing things, confusion at home and workplace are some of the symptoms exhibited by people afflicted with dementia.

Dementia is a weapon, sabotaging all the assumptions, definitions, and preconceived notions about the existence of human beings. The basic difference that differentiates a human being from other creatures is his brain. Just as the wood is eaten by a termite, the brain of the person is hollowed by dementia, though he still very much exists in his body. He cannot sustain psychological continuity because of the damage done and becomes an outcast and forlorn; completely excluded from the mainstream of all human affairs. Is it morally, spiritually, and ethically right to recognize a person only in relation to his psychological and mental state and activities?

Locke considered the thinking capacity of human beings as their core competent power over other creatures of the environment. He is in consonance with Descartes 'I think therefore I am.' Man is a rational being equipped with the capacity to reason and reflect in past, present, and future. His existence is completely dependent on his power to think, distinguish and react with the help of consciousness that is inseparable from thinking. The conscious self is tied up with the body, but the same conscious self is the person above the body. The person is a living being with intelligence, thoughts, reasoning capacity, and reflective insights. Locke makes a clear difference between 'man' and 'person'. Man refers to the hardware, the machinery called the body, while the person is referring to software, the consciousness; the basis for the person to exist, feel and react and create his personal identity.

Parfit also affirms to Locke that one's identity is upheld by "psychological continuity". He feels, like Locke, that the links that join a person's previous self to the present self involve "psychological connectedness." (Persson, 2016) In his view, psychological connectedness is a bridge that connects the shores of past and present and forms personal identity. A person's self before last week is joined with the present self by psychological continuity maintained by beliefs, memories, and desires. If we did not have any memory there would not be any consequences of reasons and results. It is clear, therefore, that for Locke and Parfit persons are just mental accumulations, storehouses of thoughts, sensations, beliefs, and desires which achieve continuity.

Alternative to this view is the SEA (situated-embodied-agent) view of the person. SEA regards the human as an embodied agent embedded in his bodily form as well as in history, culture, and in relation to others. According to this view, it is not logical to interpret psychological phenomena without an embedding context. To reduce the human being; who is the most refined and latest form of evolution; to the mere psychological phenomenon is a narrow and reductive view because the person cannot be just a sum total of connected mental states.

The situated context involves human interaction with the surroundings because human beings are not passive spectators; they participate, choose, wish, and decide the shape of their lives and characters. Their highest good is living well and bringing joy to others. Now when human beings are actively participating in the environments in which they are placed, how can they be considered independent of those environments? In contrast to Locke's concept of consciousness, the SEA postulates that human beings are placed in historical contexts of time and place and human interpretations cannot be free of them.

The eternal question; whether the brain dominates the body, has answers in these views. According to Parfit, there would not be any meaning attached to a demented person's existence if his brain cannot run its functions and regulate psychological connectedness. The person can be called a body whose expiry date is over. On the other hand, the SEA view holds out the possibility that the person's brain is not the sole cause of his magnanimous existence but his personhood is also roped in his life history and engagement with others, in his or her bodily form. This SEA view holds out the immense possibility for severely demented people showing them the light even in the darker realms, by calling their lives meaningful even without cerebral power, provided they get support from their social contexts. The reality of dementia challenges us all in many ways; it questions our understanding of relational autonomy and relational identity. What it means to be with a person who is losing some of the key capacities on which the relationship is built upon. How tragic and painful it would be to witness scene by scene the withering away of a personality, which one has nurtured for many years. How chaotic and confused it would be for a demented person to just become the object of discussion for which others take the decision. How embarrassing and disconnecting it would be not to remember the ways which one has trodden upon for many years or forget the cooking recipes, lectures to be delivered to students, or missing important assignments. Dementia does tame the independent fierce personalities of shy, dependent patients. Still Alice is a terrifying, heartbreaking, and at the same time inspiring story of Alice Howland; a celebrated Harvard professor, at the zenith of her career, happily married with three grown children when destiny casts a cruel eye on her. She realizes that dementia has slowly entered her life and mocking her achievements so far. Her memory is leaving her side, her linguistic abilities deserting her and lastly, her world starts crumbling apart, everything that she could take pride in as her achievement and has built bit by bit shatters and disintegrates. In Lisa Genova's debut novel *Still Alice* every minute detail is taken into consideration to show what exactly it is to suffer from dementia.

Dementia is merciless, cruel while snatching all the faculties from Alice, and very generous while bestowing her with all human inadequacies. Reading *Still Alice* we learn that this disease is very unkind and ugly. For example, the path that she has trodden many times, could not be traced back by her while she is out jogging. She stands at a familiar intersection and experiences a "sea of anxiety swelling furiously inside her" (Genova, 2009): she is frightened "at being inexplicably lost" (Genova, 2009). On Christmas eve she could not bake a chocolate pudding cake that she baked for many years for her children because she could not recollect the recipe. Alice recollects, "I didn't make the pudding on Christmas Eve because I couldn't. I couldn't remember a single step of the recipe. And I've made that dessert from memory every year since I was a kid." (Genova, 2009). Alice enquires about her sister's death in the later stages of dementia and experiences an emotional pain that she had already experienced in her past because her mother and sister died a long time ago and she could not remember the tragic event. Lydia responds "Mom, Anne's dead. She died in a car accident with your mother" (Genova, 2009).

Alice has dedicated her services as a research scientist and professor for more than 25 years and achieved important career milestones during her term at the knowledge hub i.e., Harvard University. This part of her

personal identity that she has sculptured so far is the first one to be hammered by dementia. Alice starts sensing “like a fraud posing as a Harvard professor” (Genova, 2009) when she struggles to try to retain memories and do her work effectively. For Alice, this is the real beginning that will put an end to her professional identity because it shows that she starts doubting herself. Alice, however, is not the only one to notice her struggle, which is clearly seen in her below-average student evaluations and due to this she is forced to leave her job, making her aware that “like the biggest part of her, the part she’d praised and polished regularly on its mighty pedestal, had died.” (Genova, 2009) This marks an end to her career and the beginning of a new life in the unexplored realms of dementia, just as Alice in Wonderland.

“Personal identity is constituted through personal relationships and public interactions”. (Baylis, 2017) It is deeply immersed in the political, social, and cultural embeddedness of a person. It recognizes that man is a social animal and moves forward in consonance with society by adding some approved behaviors and deleting some traits that are disapproved by its rules. Personal identity is a dynamic song that cannot be sung solo, it is always in concert with others; be it a public or a personal place. The identity of a person is distinct from his personality, as it cannot be reduced to inclinations and character traits. Personal identity is formed by the experiences of the whole life of a person. It is the sum total of a person’s lived experiences, constituted and co-authored, with the participation and support of others. It is like looking at one’s own self through the eyes of others wearing the spectacles of one’s own perceptions. Thus it is an identity constituting narrative “through a series of actions, interactions, reactions, and transactions” (Baylis, 2017) approved by society. It is a balance between self-ascription and ascription by others. “Persons are (and can only be) dynamic complex co-creations informed by the perspectives and creative intentions of others.” (Baylis, 2017). Personal identity is like a story created by a group in which a person exists. It is the shooting of a daily soap opera where the reactions of the audience decide the future of the series. Similarly, we are only the co-authors of our own living, writing the saga of our lives in consonance with others. Alice is slowly “cast out” by her colleagues, leaving her feeling “bored, ignored, and alienated,” no longer respected as a professional or as a friend. Alice was, Dr. Alice because she carried an academic reputation now Alice is still Alice for the reason that society is no more interested in writing her saga of life. Alice has become Still Alice freezes in a time-loop, without any forward or backward movement to disintegrate. Persons afflicted with dementia need relational support to be seen as persons, and even to experience themselves as persons.

Other than her family and career, Alice has even lost her sense of awareness. Her sense of self is sharper than her recognition of her family members, but it withers away quicker than anything else because Alice could not shelter it from dementia. Alice contemplates her whole life so far was “strange, competitive, cerebral, and privileged.” (Genova, 2009). This account shows that she is both proud and thankful for her experiences, which makes it harder for her to accept her mental decline. Alice admits to John that she is slipping away and does not “have much more time of really being herself,” (Genova, 2009) signifying that she is falling into a deep pit, never to come back. Her feelings of “a growing distance from her self-awareness” (Genova, 2009) confirm it. In due course, Alice begins to talk about herself in the past tense; when she notes it down in her diary that she was confident and successful. The use of the word ‘used to’ reveals that she has surrendered her past self, her prior qualities, and her personality and accepted that only the present moment exists for her without any hopes for the future. In the beginning, she loses her hard-earned identity as a Harvard professor, then the affectionate mother and an understanding wife, and finally the identity of a grandmother for which she waited so much. The pathetic tragedy however it was she knew all this and could not do anything about it, with all her financial resources, academic qualifications, and support of the family at her disposal. The heartbreaking tragedy is that every dimension of Alice’s identity is ultimately lost due to dementia, which is further revealed in her last moment of luminosity, when she comprehends with clarity of expression about a “pristine place” in her mind, and says, “I miss myself.” (Genova, 2009)

What happens to relationships when the brain breaks or memories fail? People with dementia become increasingly moody, frustrated, isolated, and at times aggressive. These negative personality changes impact their relationships with others in their social circle. Family members, neighbors, friends, religious groups, and people in the inner circle get influenced the most. As the disease progresses; meaningful and rewarding interactions lessen, leading to strained relationships that eventually rupture. Or they might also move in different directions, sometimes positively. Persons with memory impairment are the stagnant spectators, passive and inactive writers of their life narratives; caregivers to these burn themselves out extra in a move to write their part also. People with dementia rely on them for support because they share some past personal and social memories. It now becomes the prime responsibility of people sharing the circle of recognition and belongingness to contribute creatively to the relational identity of a demented person. It is more like a shift from Autobiography to Biography.

Alice’s illness shows how a family member’s serious illness has a drastic effect on relationships. Either a mutual understanding is formed or negative emotions surface among immediate relations.

Alice’s husband John accepts the offer of a new position and moves to New York despite knowing Alice’s intention of spending whatever time has left, with each other. When John gets to know about Alice’s illness he implores Alice to join him in New York, despite the fact that demented people cannot adjust themselves to new surroundings. Firstly there is a period of denial, and most irresponsible on his part is not to notice the symptoms of dementia in Alice, in spite of living under the same roof. Spouses are the first ones to notice the symptoms, and “someone so smart, a scientist, could not see what was right in front of him.” (Genova, 2009).

The truth-revealing realization is he has not paid enough attention to his wife and was wedded to his career more than Alice.

With her mental health deteriorating, her marriage also begins to deteriorate while her relationship with Lydia, her youngest daughter strengthens and they grow closer as she gets worse. Opposite to Alice's strong belief in formal education, Lydia first decides to go for acting instead of college and it is something interpreted by Alice as "rebelling against who we are," as brought to the notice of John. John always was one of the good parents who never objected to the ways of his children (in the eyes of his children) and Alice the bad one who questioned and suggested to her children about the ways of the world. As her condition starts deteriorating, Alice decides to read Lydia's diary in order to know her before she forgets completely, and while reading her diary Alice gets to know Lydia closely and a sense of acceptance for her daughter grows in her, to accept her daughter as she is and break the barriers so that they can come closer. Ultimately, it is Lydia who is able to understand Alice, read her confusions, and give answers without letting Alice feel ashamed of her own by asking. Genova highlights Alice and Lydia's relationship, and discusses the positive side of illness, how terminal illness brings together even alienated loved ones. Every member of her family is affected deeply by Alice's dementia, but all is well that ends well. In *Still Alice*, the paradoxical nature of the illness is discussed by bringing together mother and daughter and separating husband and wife. Dementia, a deadly disease can distant people and at the same time can bring them together as well.

Alice has metamorphosed into a new being just as in the novel written by Franz Kafka, finding it very difficult to adjust to new surroundings. Her recognition is threatened, belongingness is uprooted, but her emotional compatibility with her youngest daughter is enhanced.

Alice makes the list of her priorities when she is confronted with the fact that she is about to lose all and realizes that she values her family most and all these years she was trying to find happiness in her career neglecting her own family. She is filled with an insight when "nowhere in that list was there anything about linguistics, teaching, or Harvard" (Genova, 2009) She has understood the line 'live each day as if you are going to die tomorrow' only when she has a limited amount of time at her disposal. This reveals to her how she took her family for granted and gave importance to her career. Dementia will steal her memories over time is known to Alice very well, but at the same time, she has faith that her unconditional love for her kids is "safe from the mayhem in her mind because it lived in her heart." (Genova, 2009).

People suffering from dementia in due course lose their capacity of recognizing others, but those in relationships with them can act otherwise, they can provide relational support to people suffering from dementia. They can be people in close-knit circles or acquaintances who seek support. Those with the sharp memory and extraordinary mental capacities are granted recognition of cerebral powers but the loving wife, the affectionate sister, the adorable mother may be recognizable even without them, as these are attributes of emotive relations and are imprinted in the heart. These abstract concepts are not dependent upon forgetfulness or memory. Over time dementia wipes the memory, uproots recognition, and shakes belonging; whether it robs them of their personal identity is dependent upon all of us.

Beverly Beckham (2008) writes Alice cannot be defined in terms of dementia. Alice is *Still Alice*, respected by colleagues, and loved by family. No disease can be greater than a person's identity because illness is not an end in itself but a mere accident in the ongoing journey of life.

Neuroscientist Lisa Genova's lengthy novel marks a shift from the brain to heart in a hallmark moment in which Alice is without the cerebral power to think, discriminate or comprehend but feels, understands, and experiences love, when Lydia reads out a passage "Angels in America" to her, and she speaks slowly prolonging the vowels "It's...about...love..." (Genova, 2009) as Lydia puts the book down.

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