

# (Re)Conceptualising Dementia through Literature

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## Abstract

Dementia is widely regarded as an urgent global concern and is often termed as a 'burden' or 'tragedy'. This common perception about Dementia often leads to the isolation and stigmatisation of people living with dementia. This paper aims at arguing how literary representations of dementia can break this pattern and create a more compassionate and humane perception about dementia patients. Dementia narratives foregrounds the lived experiences of the patient and their caretakers and by doing so provides a holistic picture of a life with dementia which is absent in the biomedical narrative.

**Keywords:** Dementia; Literature; Memory; Narrative.

With the advent of gerontology and ageing studies on an international scale, there has been substantial debates regarding how we treat the older people. And this has led to the emergence of new thinking about ageing. Literature featuring the older people have played an important role in providing a positive perspective regarding the old. However, the prevalent idea regarding the 'old' is one which portrays them as a burden and as infirm. This widely held belief regarding the older people is a social construction which is fuelled and manifested by a highly consumerist society. Michel Foucault in *Discipline and Punish* had made the argument that "age and ageing are socially constructed in order to control and regulate older people and defend powerful interests" (84). Such a hostile society with the aid of policy makers and politicians would call for the privatisation of the health sector and would portray the older generation as the enemies. Anything that cannot generate a financial profit is considered detrimental to the society. Within the older generation, the recipients of the highest amount of hostility are the people with dementia.

The word 'dementia' is derived from Latin *de mentis* which means 'out of mind'. A person suffering from dementia has to endure a plethora of symptoms which makes his/her life and of the people around them, particularly their families, difficult. Therefore, when we speak about dementia, we must bring into the equation the families, communities and society. People diagnosed with dementia experience isolation and loneliness which puts them in constant jeopardy. Dementia is a severance of the basic human capability to think and to make sense of everything. Medical science is yet to provide a cure for this disease. It is necessary that a disease like dementia is understood from all possible angles and not just through the purview of the biomedical sciences. It requires a combination of different perspectives. Dementia is an attack on the very fibre of our 'being' which inevitably calls for the involvement of art and philosophy. The chances of the knowledge disseminated by the medical journals being imbibed and understood by the whole society is minimal. The people have more exposure to movies and novels. The biomedical narrative on dementia when supplemented by the perspectives of other disciplines offers a better scope for understanding the condition.

People suffering from dementia are often categorised as the 'other' primarily because of the fact that the majority of the population or society at large is oblivious to what it is like to live with dementia. And this is where literature about dementia brings in a difference. Literature about dementia portrays a person's mindscape which provides a potential source for the society to learn about dementia. Literature about illnesses can prove to be illuminating not only to the society but also to the medical professionals. It provides the medical professionals a chance of looking at illnesses and its repercussions in a new light away from the dominant medical empirical rationale. Literature provides us with a unique opportunity to learn about people we have never met and understand the nuances of their life experiences. It is possible that we might learn more about people from literature than from logically analysing their lives. Martha Nussbaum argues that, "Our experience is, without fiction, too confined and parochial. Literature extends it, making us reflect and feel about what might otherwise be too distant for feeling" (156). Even the most private, distasteful, embarrassing of experiences can find itself a place of representation in literature. Literature about dementia has the power to bring people living with dementia out of our blind spots and cure us of our prejudices regarding dementia. There are ethical hurdles when it comes to doing research about people with dementia. Literature provides anonymity which considerably reduces the ethical dilemma. Henrik Ibsen in his famous speech delivered to the students of Christiania had opined that "Writing is seeing" (Meyer 391). A

piece of literature is like a pair of glasses with which the readers see the world. And literature about dementia provides new visions about dementia. It can be argued that a medical journal can also speak about dementia in a new light. But the fact of the matter is, the impact that it can bring on the society will be very different and very minimal because the target audience will mostly be confined to medical personnel alone. Literature brings to the front what is hidden and inexplicable. The narrative aspect of literature provides the readers with a different and more effective level of understanding. The medium of stories or narratives have had a resounding impact since time immemorial. Fiction is an escape from reality but at the same time it is an interpretation of reality. Stories are a portal through which we can see and comprehend someone else's life. Through stories we are able to 'live' the life of the 'other'. Stories have been a vehicle of moral values throughout the human history. Even Jesus resorted to parables to teach moral values. "All narratives carry moral messages in one way or the other and images of the moral world" (Goodson and Gill 133). But literature need not always be didactic. In fact, good literature is seldom didactic as it provides a space for the readers to investigate and figure out a meaning or message for themselves. Learning only takes place when the reader is actively involved in the process. A story does not have the prerequisite to be factual in order to be true. The source of every story or fiction is life. According to Nussbaum, "certain truths about human life can only be fittingly and accurately stated in the language and forms characteristic of the narrative artist" (133). The myriad literary representations of dementia or any other illness for that matter can help to deepen and humanise our attitude towards people living with the condition.

The different types of literary genres including biographies, autobiographies and fiction can broaden our understanding of the impact of dementia on the patients as well as on those around them. Iris Murdoch is a reputed British author who had developed dementia during the twilight of her life. The outside world was made aware of this fact when her husband, John Bayley, published *Iris: A memoir of Iris Murdoch* (1999). In this very open and upfront account of Iris' life, her husband explicates their life together in the past and in the present where he performed the role of a husband as well as a caretaker of Iris with dementia. John is able to recalibrate their relationship and make all the necessary adjustments. He remarks, "the exasperation of being followed about the house by Iris is as strong and genuine, as is my absolute need for her" (Bayley 45). He speaks about Iris' fear of other people when he is not around, "it is so piteous that I cannot bring myself to arrange for carers to 'keep her company' or take her to the age therapy unit" (54). John ponders upon the question of

identity in dementia. He somehow finds solace in the fact that he may not have known Iris fully. He remembers Iris as someone of an elusive nature and recounts that:

Iris once told me that she had non stream of consciousness. She did not talk about herself. They say people with a strong sense of identity become the worst dementia patients. They cannot share with others what they still formulate inside themselves.(48)

The reader can see John struggling as well. John remarks, “Does Iris speak inside herself of what is happening? How can I know? What is left is a terrible expectancy. When?” (56). John Bayley has managed to provide a sincere depiction of how he made the necessary adjustments and requirements to negotiate with dementia while keeping his relationship with Iris pristine. He does not shy away from accepting the frustrations that come along with it, but his account is a very important example of how the patient and the caregiver together embark on the journey with patience, solemnity and love.

Understanding the mind of someone suffering from dementia is of utmost importance. Eric Rill’s novel *An Absent Mind* (2015) gives us an effective portrayal of a mind crippled by dementia. The protagonist, Saul Reimer, with the diagnosis of dementia experiences a severance from his earlier superior intellectual life. Saul’s brain has become, “a short wave radio, mostly static that occasionally find the station”(Rill 54). Saul’s brain is failing to make connections and make sense of everything around him. Rill’s novel through the character of Saul Reimer portrays how dementia fragments the memories, creates temporal distortions and forces the mind into a struggle to make sense of the reality.

Christine Bryden, an author who lived with dementia, carefully documented her journey in two books titled *Who will I be when I die?* (1998) and *Dancing with dementia* (2005). In both works she ponders upon the question of self, what constitutes our self and what is the ultimate meaning of self. The readers are engaged with the questions regarding the relationship between memory and self. Does losing memory mean losing your self? What becomes of our identity without our memory? If we are unable to make sense of our past what are its repercussions in the present? Bryden provides us with answers in her second book *Dancing with dementia*. She says, “My journey with dementia has been a journey of self discovery about who I really am”(Bryden 69). She goes on to say, “by accepting this journey of change and adaption, we can dance with dementia and

chose life in the slow lane” (74). Bryden rediscovers her *self* in her journey with dementia and through her books she shares with the world invaluable lessons about dementia. Her books plunge the readers into the life of a person with dementia. The reader gets to hear broken, laborious and fragmentary conversations. The reader gets to comprehend the change in attitude of others ever since the dementia diagnosis. The reader also gets to see the waning physical and mental abilities of the patient which render them infirm. Bryden states that the purpose of her writing is to:

Try and write down my experiences, not just about me and my girls, but also to explain dementia in a way that lots of people might be able to understand this physical disease, which whittles away at the brain until life eventually ceases. (34)

Another author who spoke about his life with dementia is Thomas De Baggio in his book *Losing my mind: An intimate look at life with Alzheimer's* (2002). De Baggio recounts in the early pages of the book that, “at the age of 57 I was equipped with a thin body free of aches and pains. I looked forward to a life to rival my mid-western grandmother’s 104 years” (56). But to his dismay he soon finds out that he is spiralling into the abyss of dementia. He vividly describes the day he got his diagnosis:

Then came a beautiful spring day later that year. It was the day after the tests were finished and the results reviewed. It was the day I was diagnosed with Alzheimer’s. What time had hidden was now revealed. Genetic secrets, locked inside before birth, were now in the open. I became a new member in the parade of horror created by Alzheimer’s. (54)

De Baggio through his writing portrays the different stages of denial, frustration, anger and finally acceptance. The diagnosis of any illness is a difficult pill to swallow. Accepting it will take time and the process can be tumultuous. The impact of a diagnosis upon the patient is profound. De Baggio tells the readers about his reaction to his diagnosis, “at first I viewed the diagnosis as a death sentence. Tears welled up in my eyes uncontrollably; spasms of depression grabbed me by the throat. I was nearer to death than I anticipated” (65). And later he tells the readers that he is on the road to acceptance, “A few days later I realised good might come of this” (44). De Baggio also recounts that the reason he is writing is “to break through the sense of shame and silence Alzheimer’s has engendered” (47). He also finds a sense of purpose for his life with dementia in writing. He opines, “Writing is a truly liberating experience for me and I do not want

to give it up" (67). De Baggio reinvents himself through his writing, "The words in my brain are silent, and the flood of sentences begins only when my pen unleashes a flood of writing memory" (87). De Baggio's account is a testimony to the fact that it is possible to reinvent a resilient, persevering version of your self in the face of a life altering illness like dementia.

Jeanne Lee is another author who has recounted her experience with dementia in her book *Just Love Me: My life turned upside down by Alzheimer's* (2002). It is a summary of her diary entries of the years she lived with dementia. She had felt the dire necessity to write and to share her experiences with others because ever since the diagnosis she had begun to experience terrible loneliness. The title of the book itself is a plea. She recounts that the purpose of her writing is "to help open things up for all of us, and if not for us, then for those that will follow" (Lee 44). After the publication of her book, Jeanne Lee continued to be a public figure giving seminars and lectures on dementia to the public and other patients. She divulged her lived experiences of dementia to create awareness among other patients and their families. She was able to negotiate with the loneliness she had felt when she shared her experiences with others.

Literature about dementia promotes a patient centred approach where they can openly speak about their lives. Dementia is a life altering disease which forces the patients to change the very dynamics of their life. Literature invites the focus on the patients and their subjective illness experiences whereas in the biomedical narrative their lives get reduced to a mere list of symptoms and medicines. Dementia narratives give insights regarding how a person with dementia perceives himself or herself in the society. The dementia diagnosis would instantly render the outside world a foreign place where they are often not welcome. The family, friends, neighbours and colleagues would begin to formulate an unenviable image of them. People with whom they had earlier shared intimate life experiences would now begin to see them exclusively through the lens of dementia. As a result, the person with dementia would begin to feel isolated from everything. They will begin to feel a level of loneliness which they had never felt before. The outside world becomes a hostile place while they struggle to figure out their inside world which has been disfigured by dementia. This hostility from the outside world aggravates their misery. Jeanne Lee's book *Just Love Me* is a plea and the very purpose of her writing is to counter her loneliness. John Bayley in *Iris: A memoir of Iris Murdoch* recounts how "Iris felt a fear of other people when he was not there" (Bayley 34). For the person living with dementia, "the disease is both a biological disease and a negative social experience" (Vittoria 370).

Dementia should not be held as the defining characteristic of the patient. They are as much a part of the society like the others. They should not be in any way isolated from the rest of the society. Dementia narratives have the potential to create a sense of identity and empowerment. Beard argues that, "reading or listening to narrative accounts of a person living with Alzheimer's can help change societal perceptions of the disease, reduce stigma and depersonalisation" (230).

Literature provides a unique and effective opportunity to understand the lives of the people living with dementia. Dementia narratives are not an objective account of the illness but a subjective account of how dementia alters the very lives of the patients as well as the people around them. The medium of writing makes it possible to instil a personal and emotional dimension to the discourse on dementia. In biomedical narratives the voice of the patient or of the caretaker is often muffled which prohibits us from having a comprehensive understanding of the illness. Dementia narratives is a way of ensuring that the voice of the patient or of the caretaker is heard. It takes us beyond the biomedical narrative, which is often a list of symptoms and medicines, to give us a panoramic view of a life with dementia. Dementia narratives are written from the point of view of the patient which makes it flexible to move beyond the empiricist framework of the biomedical narrative. And as a result, it opens up an entire new avenue of knowledge about dementia.

Literature can effectively reduce the stigma associated with dementia by reconfiguring the attitude of the society towards people living with dementia. Our perception about dementia is formulated from the existing dominant narratives propagated by the authorities (government and healthcare) which often portrays the dementia patients in a negative light. Literature can break this pattern and change the societal perception of dementia for the better. People living with dementia would require all the support that they can get from the people around them. And for that to happen the stigma and prejudice surrounding dementia must vanish. Dementia narratives have the potential to initiate a change from "They are NOT us" to "They are US". Literature creates a pathway to the mind of the person with dementia. It shows us the state of mind before dementia disfigured it. It shows us how much the mind got disfigured and state of fear and uncertainty that the person is in. Dementia narratives enable us to empathise with the patient. And when empathy steps in, all the stigma, prejudice and aversion is bound to disappear. It will result in the improvement of the well being of the patient as well as the improvement of the society as a whole.

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