International Research Journal on Advanced Engineering and Management
https://goldncloudpublications.com
https://doi.org/10.47392/IRJAEM.2024.0420

e ISSN: 2584-2854
Volume: 02
Issue: 09 September 2024
Page No: 2850-2855

Social Dynamics and Personhood in Alzheimer's disease Narratives: An Analysis of the Self in Alzheimer's Autobiographies

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Abstract

Alzheimer's disease (AD), categorized as a disability by the World Health Organization (WHO), has been the most common form of dementia affecting sixty to seventy percent of patients. While medicine has offered multiple perspectives on AD, literary accounts by caregivers and family members initiated socio-cultural conversations around AD. However, the ableist perspectives did not portray the stories on the experiences of the patients but rather focused on caregiving. This was altered by the publishing of several Alzheimer's autobiographies that document the disease, showing the reality of AD. Although each AD experience is unique, the common factor has been how memory loss and other accompanying symptoms make them lose their selves through the process. The self, in this context, relates to the identity and personhood carried by the patients. Personhood is defined by Tom Kitwood (1997) as the status bestowed upon a person in the society by the others and how they are treated. Studies on personhood in dementia and AD have pointed out the loss of personhood through memory loss and cognitive decline. However, through readings of autobiographies, one understands that the personhood is not all lost, and whichever part is lost is tried to be reclaimed by the patients in multiple ways. This study aims to read through parts of the autobiographies chosen – namely, On Pluto: Inside the Mind of Alzheimer's by Greg O'Brien, Somebody I Used to Know by Wendy Mitchell, and Losing My Mind by Thomas DeBaggio – and analyze how this personhood is reclaimed by maintaining an active social life. This study looks to contribute to the growing realm of disability studies by choosing Alzheimer's autobiographies as the primary focus and remove the stereotypical ableist lens on AD.

Keywords: *Alzheimer's writing, Autobiographies, Disability studies, Narratives, Personhood.*

1. Introduction

1.1 Alzheimer's Disease

Alzheimer's Disease (AD) is defined by the National Institute of Aging (NIA) as "a brain disorder that slowly destroys memory and thinking skills, and eventually, the ability to carry out the simplest tasks". Named after Dr. Alois Alzheimer in 1906, the disease has been categorized under dementia, which includes other neurodegenerative diseases like Lewy-body dementia, Fronto-temporal dementia, Vascular dementia, Mixed dementia, etc. The World Health Organization (WHO) has declared that AD is the most common form of dementia contributing to 60% to 70% of dementia cases. Although There have been recent progresses in medical studies of Alzheimer's, medical perspectives offer limited information on AD. They also do not include social aspects of AD that play a significant role in the experiences of patients of AD. Martina Zimmermann (2017) begins her book The Poetics and Politics of Alzheimer's Life-writing by discussing her experience as a neuroscientist with an Alzheimer's patient, who speaks to her well in the morning and forgets her in the evening. Despite dealing with AD patients as part of her profession, she says, "The encounter with the elderly lady confronted me with questions whose consideration seemed to be absent from mainstream narrative, namely how do patients and caregivers cope with dementia in daily life; how do they experience memory loss; and above all, how do they negotiate with this very narrative" (5). This proves the lack of relationship between medical and social perspectives in AD and dementia narratives. [1-5]

1.2 Illness Writings

Kathlyn Conway (2007) clarifies that narratives that glorify illness experiences usually end in finding a hopeful future or a cure for the illness. However, she opines that journeys of illnesses carry a lot of pain and suffering which are not discussed enough in these narratives. She, as a survivor of cancer, discusses the accompanying mental illnesses like depression and how writing about her struggles helped her achieve narrative catharsis. Her works discuss the hopelessness of a fatal and chronic illness. She also iterates, "Writing gave me the freedom to be honest in a way that was not always possible in conversation, where, I found, people sometimes cut me off or subtly let me know that they wanted to hear only a particular version of my experience" (2). Alzheimer's autobiographies portray this exactly and break stereotypes around memory loss, linguistic and language depletion associated with dementia in general. Although cognitive and linguistic degeneration is witnessed in the lives of these writers as the disease progresses, the stereotype affects them right from the diagnosis. Wendy Mitchell in her work Somebody I Used to Know claims that the financial aid from the government was cut off because she was functioning as an independent woman. She feels that she is being penalized for "trying to cope" (138) albeit "with difficulty" (151).

1.3 Personhood

Personhood as a concept in dementia is extensively discussed by Tom Kitwood (1991) in his work Dementia Reconsidered: The Person Comes First. He defines it as "the standing status that is bestowed upon one human being, by others, in the context of relationship and social being" (8). The term 'person' here is not directly synonymous with 'human being' but is used according to the treatment of that person by others. Kitwood says that the experiences of an Alzheimer's patient depend on multiple social and cultural factors, but most of them paint a different picture from the negative and deterministic views seen in the standard paradigm of AD. Several Alzheimer's autobiographies have proven that this personhood has been either altered or denied in ways they did not expect. This study aims to understand how they reclaim this personhood through maintaining the existing or sometimes building new social circles and by redefining their 'self' through action. [6-8]

2. Literature Review

This study has considered three Alzheimer's autobiographies namely On Pluto: Inside the Mind of Alzheimer's by Greg O'Brien, Somebody I Used to Know by Wendy Mitchell, and Losing My Mind by Thomas DeBaggio. Studies on personhood in Alzheimer's patients have spoken of the socio-cultural approaches to the disease affecting their illness experience, which has in turn affected their personhood in terms of losing family and friends, social life, employment and so on. Illness writings are a way to bring these out. Neeraja S (2016), refers to Bryan Turner (1997) and Paula Treichler (1998) and says, "disease is a language, the body is a representation, and medicine is the political practice" (6,7). Although illness writings include narratives of caretakers, family members, biographies, etc., autobiographies give power to the victims of the disease to narrate their experiences. Diane Pierce Hendrl (1998) says that the best place to understand illnesses is to look at the most personal and subjective narrations (773). Illness writings also allow the readers to understand the person's view of self, which sometimes can be influenced by how others view them. Kathlyn Conway (1997) in her work *Ordinary Life: A* Memoir of Illness talks about the need for illness writings to bring out the pain and struggle of illness journeys rather than focusing on the cure and a hopeful ending. Arthur Frank (1993) in his essay 'The Rhetoric of Self-Change: Illness Experience as Narrative' says that illness narratives are "significant means for studying the social construction of illness as a rhetorically bounded, discursively formulated phenomenon" (41). Alzheimer's writings stand as an epitome of illness narratives as discussed by Conway because of the degenerative and fatal nature of AD. Although unfortunate, these narratives bring out the unique journeys of patients, proving that no two journeys are similar.

2.1 Aging studies

Aging studies have brought into focus the difference in experience, mental acuity, health, capacity, etc., among people of the same age. Studies since the 1840s have fixed sixty years and above as the threshold for studies on aging or gerontology (Stuart-Hamilton, 2011) although it acknowledges that a person does not turn old overnight after turning sixty. The process of aging is considered to begin at that age. Elizabeth Barry and Margery Vibe Skagen (2020) point out the non-linear progress of aging and that is probably one of the reasons why literary and cultural studies have sidelined gerontology. Helen Small (2007), however, argues that generalizations on aging can be countered with the opposite as well. Her work also insists that she reaches "no great conclusions" (265). This stands testament to the fact that old age is perceived based on what carries value in one's life. [10]

2.2 Alzheimer's autobiographies

Studies on Alzheimer's writings have advocated for reading patient-authored narratives for a better understanding of AD and dementia. Anne Davis Basting's (2013) ableist view that dementia narratives must be placed away from mainstream literature because they do not match the illnesses has been refuted by many scholars later. Martina Zimmermann (2017), based on her readings of Alzheimer's autobiographies, says that caregiver narratives rebuild the inner world of the patients from an ableist perspective. She also points out that anthropological studies have proven coherence in narratives by dementia patients. She says that these narratives "will support a more comprehensive understanding of patients' poetic choices as being politically driven" (11).

2.3 Research gap

Studies on personhood have focused on care homes and the environment in such places. For instance, Jessica C. Robins (2019) talks about the positive and upbeat environment in a care home in Poland, which surprised many. She says that it is perceived that "social death is often a result of diagnosis of AD" (1). Another study by Jayne Yactzac (2018) discusses the usage of everyday objects to support personhood of AD patients. These studies look at AD and the treatment of the patients from a personhood perspective based on their diseases. This ableist perspective disallows the fact that personhood is based on the fact that an AD patient is a person. This study aims to understand how the social death is dealt with by patients themselves and how they aim to reclaim the social life and personhood that AD seems to have taken away. [9]

3. Methodology

This study has taken three autobiographies and applying qualitative study and narrative inquiry for a better understanding of personhood in AD. Webster and Mertova (2019) are of the view that narrative inquiries are "set in human stories of experience" (1). They reiterate this by saying that human experiences provide researchers with a strong framework for any study. While several methodologies focus on forming opinions based on numbers and data, narrative inquiry allows a researcher to understand the "complexities of human centredness in research" (3). This methodology also increases the possibilities of interpretation and reinterpretation. Alzheimer's writing requires narrative inquiry not only to break the stereotypes around AD but also to understand the uniqueness of experience of every AD patient. The evidences lie in the stories themselves and the liberatory potential of self-representations increases the possibilities of correct understanding of AD experiences. Pinnegar et al., (2007) say that words are used as data not as a means to reject numbers but as a way to not lose the nuances of experience and relationship in a given situation (15). This study relies on this methodology to include such nuances, which often remain ignored in several other methodologies. Narrative inquiry also allows space for the uniqueness of every experience of AD since no two experiences are the same. [11-15]

4. Discussion

4.1 Rebuilding Personhood Through Social Experiences In Alzheimer's Disease

Autobiographies serve as a way to assert narrative identity by the writers. There have been several studies discussing identity and the loss of it in disability studies and Alzheimer's writings. L.C. Hyden et al., say that autobiographies become a way to focus on the stories of the autobiographies that "in some way show the essential aspects of the teller's identity" (205). Through these autobiographies, one understands that personhood is lost right from the medical diagnosis. Wendy Mitchell says that the lack of medical treatment or cure makes her "feel abandoned by the doctors who diagnosed me" (59). There is also a sense of denial shown by the family members. In the case of O'Brien, it is understood that his family noticed signs of memory loss in him but chose to ignore it. His son is engulfed with rage when he is informed of his father's diagnosis. The sense of abandonment from both medical and social circles shows that personhood is slowly lost in the journey of Alzheimer's disease.One of the ways in which the writers of these autobiographies socialize is by becoming part of volunteer groups for medical research on AD. Mitchell compares this phase of AD with her reserved childhood when she did not interact with people around. However, she relies on the volunteer group to have regular social interactions and the comfort it brings her. Initially, however, it disheartens her to see that no one looks like her in the volunteer groups because of early onset of AD, which is a rare form. As her search for personhood continues, she involves herself in multiple activities that keep her brain engaged and active. These independent activities are, however, perceived differently by the ableist society. Mitchell says, "It's more to do with what they were expecting, what they had prepared themselves for" (141).DeBaggio also volunteers for medical research and during this reclamation of personhood, he recalls his younger days when he was focused on saving money for retirement. Upon reaching retirement, the regret of not being able to utilize the money as he wanted to sets in. He also regrets not travelling as a youngster and being frugal in his spending. O'Brien creates a routine for himself and stays in touch with his friends to maintain the personhood. His friends share several humourous moments with him, making him feel included even after the diagnosis. One of them asks, "You back from your planet yet?" (234) normalizing lighter and humourous discussions of the disease. The difference in their social experiences is clearly shown in the fact that DeBaggio seeks validation from his social life while O'Brien sticks to his routine and tries to find ways to cope with AD. [16]

4.2 Social Spaces And Personhood

Gaston Bachelard (1964) was a pioneer in associating spaces with human emotions and feelings. Social spaces, both inside and outside, play a major role in defining Alzheimer's experience. Personhood, in the context of social spaces, is defined by the attitude of family and members of the society towards the patients. DeBaggio, in his work, narrates an incident where he was not assisted by the lady at the photocopy place and it eventually stopped him from venturing out to such spaces. Personhood is also lost when assistance is not provided when required. He mentions that he felt crippled for the first time since the diagnosis. Mitchell once misses her bus stop and wanders to a different part of the city unable to find her way back home. She calls the world "increasingly hard work to live in" (129). DeBaggio goes fishing every week because "it is the only way society allows me to be a kid again, and it allows me to have time with my son" (166). As a way of maintaining a routine and spending time in the outside space, it is evident that he was helpless in other situations and has resorted to being with his son doing an activity that makes him feel like a normal person.O'Brien continues going to his office to maintain a normal life but his cognitive decline and memory loss do not allow that for long. He explains the title of his book *On Pluto* because it acts as a metaphor for an outcast and something distant from the living world. In his words, "You can't hear much on Pluto. It's a dark icy place, dense with denial, isolated to the point of impenetrable peace" (110). This is a result of lack of inclusivity and the fear of being lost in the outside space.The sense of lost self and the lack of inclusivity in social spaces contribute to loss of personhood in AD experience. This takes the study to define or redefine personhood not only based on social circles but also on personal sense of self. Robbins says, "personhood consists of ideals and practices, each of which can be analyzed on their own terms" (4). This comes as a result of understanding that a bifurcation of personhood based on dependence or independence does not suffice. The concept of personhood can be related to dependence, independence or "other practices through which personhood is created" (Robbins, 4). Placing this in the context of AD, through the instances mentioned, it is understood that personhood is dependent on one's sense of self and treatment by others in the society. [17]

4.3 Reclaiming the lost personhood

In Alzheimer's writing, one understands that the patients have to overcome the bias in their own minds as their sense of self changes. For instance, the change in routine affects all the three writers of the autobiographies chosen. O'Brien is forced to quit his job, DeBaggio is forced to be out of his nursery business, and Mitchell is forced to live a restricted life for the fear of being lost. This takes a toll on their personhood as they try to feel like a normal person by setting a routine for themselves. In a culture like in the United States of America where independence is valued even at old age, the writers exhibit their desire to remain independence and lead a seemingly normal life as much as they can. Mitchell mentions that her friends chose to remain out of touch despite her attempts to contact them. One of the immediate possible ways for her to maintain a sense of belonging in a community was to be a part of research volunteer group. However, it does not have a significant impact in her social life because the others are much older than her. She continues to be a part of research but searches for other ways to socialize. She chooses to bake for a charity on a weekly basis, and she empathizes with them as they are also secluded from normal life in a way. She also considers moving to a quiet neighbourhood because the noise outside overwhelms her. The outside space does not allow her to walk or go on her cycling routine due to lack of inclusivity. She says, "I'm numb inside, let down by a system that isn't willing to support people with dementia to stay at work, that cannot adapt and change like those of us living with it do" (86). She realizes that cycling keeps the foggy brain away and allows her to think clearly. However, the noise and crowd stop her from venturing outside even for walks. So, her way of maintaining and reclaiming personhood is by maintaining a routine, taking every day slow and allowing the symptoms of cognitive decline to take their course. O'Brien chooses to have an active life by driving his car by himself and having a strict routine to follow. However, he is stripped of his credit and debit cards, property rights and other basic rights, thereby stripping him of his personhood partially. His lawyer and family members insist that he give up on all financial control and responsibilities. His way of reclaiming personhood is by maintaining a strong relationship with his friends and meeting them often. He claims the inside spaces like his home and creates a routine to feel normal. He uses his treadmill at even odd hours like 2 AM to clear his mind of hallucinations and cloudy thoughts. He also works on multiple podcasts, speaks at conferences to raise awareness on AD experiences. He also plans outdoor activities including going on long drives in his car despite losing his way at times. When he loses his way, he allows himself to drive until the cognition is back to normal. He claims his space as his own and makes it his own to reclaim personhood. DeBaggio, like Mitchell, volunteers in research groups and forms a community. He is respected, his feelings and validated in that environment. However, he follows two important steps in his daily routine – morning walks during which he records his thoughts, and fishing weekly with his son. It is observed that all three autobiographies involve urban spaces. Henry Lefebvre (1991) says that modernity and urban spaces have become areas where people take part in multiple activities "until they become unrecognizable, entangled situations" (2). These spaces are supposed to be a melting pot of lifestyles, cultures, and activities. Through Alzheimer's autobiographies, however, it is observed that these spaces both include and exclude them in different ways. They include their lifestyles by giving them access to parks, roads, and being in the midst of the hustle and bustle of urban spaces. However, these spaces have also rejected them as they are unable to cope with the hustle and bustle. [18]

Conclusion

Alzheimer's autobiographies have proven that the sense of self carried by the patients is also an integral part of personhood. To overcome the stereotypes, claim a sense of self and eventually reclaim personhood through social life takes immense energy and patience to attain. The loss of self comes from “others’ failures to recognize them as legitimate social persons” (Robbins, 5). This shows that it is a collective responsibility to ensure maintenance of personhood in patients of AD. Through autobiographies, it is demonstrated that personhood can be maintained through strict routines, maintaining social circles, and practices that make one feel independent. The writers have been observed to be organized to assist in memory loss and cognitive decline. It is also observed that physical activities help in clearing foggy minds and it is a way to hold control of their lives. These instances embody the importance of personhood in both dependency and independence so that they feel human and included in society. [19]

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