

Reconstructing Selfhood: Analysing Alzheimer's Narratives in Wendy Mitchell's *Somebody I Used to Know* and her Digital Presence

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Abstract

Autobiographies have been an important part of understanding both personal experiences and social constructs. Patient narratives of Alzheimer's disease are rare, owing to the disease's effect on one's cognition. However, there have been multiple narratives over the last decade or so, changing the social constructs around cohesion and narrative capabilities of Alzheimer's patients. With technological advances assisting publishing these narratives, digital spaces like social media and blog spaces have made it easy for the patients to communicate to a large audience, rather than only depend on publication of books, which only a few privileged can achieve. This study takes one such example in Wendy Mitchell's autobiographical book *Somebody I Used to Know*, her blog space *Which Me am I Today?*, and her Twitter handle to draw a correlation between narratives in autobiographies and digital spaces, thereby allowing one to delve deep into the lives of Alzheimer's patients rather than create assumptions based on medical and fictional narratives. Prior research has looked at these separately evidently disconnecting books and digital publications. This research looks to understand how digital narratives through blogs and social media contribute to, and expand upon the autobiographical representations of Alzheimer's disease. A comparative analysis looks to explore how these digital platforms offer unique insights to the lived experiences of Alzheimer's patients compared to traditional autobiographical books. The theoretical framework of spatial criticism has been applied to understand how physical and digital spaces influence the representation of Alzheimer's experiences. It is also used to analyze the new possibilities of narrative techniques and interactions opened by digital spaces.

Keywords: Alzheimer's disease; Alzheimer's narratives; Digital narratives; Disability Studies; Selfhood; Spatial criticism.

Introduction

The Alzheimer's Association defines Alzheimer's Disease as "a type of dementia that affects memory, thinking and behaviour". According to WHO, Alzheimer's Disease (AD) is the most common form of dementia affecting sixty to seventy percent of people diagnosed with dementia. AD is a progressive degenerative condition that affects a person's cognitive skills. As a result of AD and its progressive symptoms, cognitive and linguistic abilities of the patients reduce with time, thereby affecting their communication abilities.

Literary representations of AD

Literature's representation of dementia and Alzheimer's disease takes one back several centuries, although the characters were not formally or officially introduced as characters with these cognitive conditions. For instance, King Lear exhibited symptoms of hallucinations and motor difficulties on multiple instances, which are clear indications of Lewy body dementia. While traditional interpretations categorized him as a mad person, several contemporary stage adaptations portray him as a character struggling to live with dementia. Don Quixote has shown audio-visual hallucinations, sleep disorder and rapid eye movements and several interpretations at a later period confirm that he might have had dementia (P. J. Garcia Ruiz et al., 1999).

Beyond literary representations in stories, however, discussions on Alzheimer's disease and dementia were predominantly based on science and medicine as social perspectives remained sidelined for a long period. Martina Zimmermann says, "Throughout the 1970s and 80s, research into Alzheimer's disease was essentially exclusively the domain of biomedical sciences" (*The Poetics and Politics of Alzheimer's Disease*, 2017, p.4). It was not until the late 20th century, with the formation of associations like the Alzheimer's Association (1979) and Alzheimer's Disease International (1984), that there was a sociopolitical approach to Alzheimer's disease. Literature joined force and multiple representations of Alzheimer's arose in the form of fiction, autobiographies, and caregiver accounts. It was inferred that the medical studies "matched the mainstream narrative very little" (Zimmermann, 2017, p. 6).

Illness writings

Illness writings, especially autobiographies, have been a prominent part

of literature.

Kathlyn Conway says that the recurring themes of positive and optimistic endings in illness writings have camouflaged the reality of illnesses and the lasting physical and mental impact of the trauma they bring (Conway, 2006). Therefore, narrating dementia seems like an oxymoron, considering that cognitive abilities are the first to be affected by the disease.

Narrations in dementia also involve stories from the long past, which are repeated and observed as the “frozen segments” of their lives. (Hyden et al., 2009, p. 206). Hyden et al., also suggest that these repetitive narrations should be viewed as solutions rather than mere symptoms or problems. However, autobiographies by authors like Greg O’Brien, Thomas DeBaggio, Diane Keaton, Wendy Mitchell, etc., prove that the narrations of dementia and AD go beyond stories from the past. They list the struggles of everyday life, owing to the non-inclusivity of the ableist world and the lack of medical and scientific backing. As Conway narrates her journey through cancer thrice, she blames herself for being a worse patient than several women she met during the chemo sessions. However, she infers later that “each woman’s story was completely different, depending on the circumstances of her life” (Conway, p. 5) despite undergoing the same treatment. Placing this in the context of Alzheimer’s writing, all the writers of autobiographies insist that it is their story and they cannot collectively speak for the experiences of everyone facing AD. This is because multiple aspects of their lives including financial status, cultural acceptance, family support and the availability of people to take care of them during cognitive decline impact their experiences with the disease.

Wendy Mitchell’s autobiography and blog

Wendy Mitchell is a prominent figure in both literary and social activist circles. Born in the UK and working with the British National Health Service (NHS), Mitchell was diagnosed with an early onset of Alzheimer’s disease in 2014 at 56 years old, forcing her to retire from service. Her experiences with AD were unique, owing to the early onset, which kept her determined to participate in research work to ensure medical progress for future generations. Her first autobiography in 2018 titled *Somebody I Used to Know* was a culmination of her activism and desperation to voice out her life with AD, which is unlike how it is widely perceived. Her determination to show the world the pain and frustration that accompany the disease while keeping her brain active through multiple activities is visible in her work. She published her second book titled *What I Wish People*

Knew about Dementia in 2022, while her third was published in June 2023 titled *One Last Thing: How to Live with End in Mind* and it discusses the painful realities of facing death and end-of-life phases that are inevitable with dementia.

Her blog *Which Me Am I Today?* was begun as a way to continue her autobiographical narrations and document her everyday life with AD. She says in her blog, "...although we've been diagnosed, people like me still have a substantial contribution to make; we still have a sense of humour; we still have feelings". This study aims to understand and analyze these contributions and how they have broken stereotypes around AD and normalized talks around journey with AD until the very end.

Review of Literature

Alzheimer's Disease (AD) was first coined by Alois Alzheimer on November 3, 1906, and has been in use ever since. Although the term was coined then, literary works have shown characters with symptoms of AD and dementia through different periods.

Autobiographies were first introduced by William Taylor in 1797 as an umbrella term to cover all writings of personal experiences. Later Robert Southey redefined it in the *Quarterly Review* in 1809 and it was used in its current sense for the first time. As literary history defined and redefined autobiographies through various movements, Albert E. Stone defined that autobiographies are "simultaneously historical record and literary artefact, psychological case history and spiritual confession, dialectic essay and ideological testament" (*The American Autobiography: Collection of Critical Essays*, 1981, p. 2). This created an inclusive definition by ending speculations and arguments over what can be considered autobiographies and their contribution to literature.

Illness writings have found their way into literature as several people wanted to document their journey through various traumas. However, most of these fell under hopeful and optimistic stories, withholding the truth of the awful pain and hurt illnesses bring (Conway, 2006). Writing provides an escape from the painful journey, in which sometimes death is inevitable. Illness writings also pave the way for a better understanding of the social construction of illness and the stereotypes revolving around specific illnesses (Frank, 1995).

AD has been constructed as a disease of the old destroying their cogni-

tion, leaving them incapable of thinking. However, anthropological studies have proven coherence in narratives by patients of dementia and AD (Zimmermann, 2017). Patient narratives put their personhood first rather than the disease itself, thereby maintaining their identity as individuals rather than dictated by AD. It also puts the onus on the caregivers to understand how it affects each person differently and the importance of placing the person at the focus and not the disease (Kitwood, 1997).

Spatial Criticism

Spatial criticism came into discussion largely based on how it is compared with temporal aspects of life. Space, which was initially viewed as static and anti-temporal (Joseph Frank, 1945), came to be known to exist alongside temporality and how “time is the soul of space” (W.J.T Mitchell, 1980). Inside and outside spaces were analyzed under the concept of ‘topoanalysis’ (Bachelard, 1957) and were given specific roles to play.

Alzheimer autobiographies discuss certain spaces, especially homes, with vivid details and memories from the past. For instance, Greg O’Brien and Thomas DeBaggio reminisce about their childhood homes as their happy spaces and one can feel in their words the yearning to go back.

Digital Spaces

Digital spaces have now fused the inside and outside spaces by giving people a chance to connect to the outside while being inside. The COVID-19 pandemic was an epitome of using digital spaces to connect to the outside world while being restricted inside homes.

Several authors of Alzheimer’s writing have combated the non-inclusive ableist world by connecting to society and creating communities via digital spaces. Digital spaces blur the line between privileged and less privileged sectors, thereby allowing anyone to create free accounts on social media or blog accounts to narrate their experiences.

Digital Technology and Illness Writings

Digital spaces bridge the gap between accessible and inaccessible spaces in the ableist physical spaces in everyday life. Technology plays a role in assisting people connect and interact with people, friends and strangers, globally. Richard Deitsch, a sports journalist, shared a photograph of his friend and his brother celebrating the brother’s win in NCAA hock-

ey championships. His invite to share photographs of the best moments garnered global attention, prompting several of his followers on Twitter to post their pictures depicting the best moments of their lives and others. This digital space became one of narration without many words, but presenting some intimate and vulnerable moments of people who joined the narration. Alasdair Macintyre's *After Virtue, A Study in Moral Theory* presents that storytelling forms the basis of human connection. In his words, narrative is "the basic and essential genre of the characterization of human actions" (Macintyre, 1981, p 194).

Narrative "induces a sense of social connection, including narratives shared in social media" (M. Rompey, 2017, pg 1042). Writers of Alzheimer's autobiographies have perpetually discussed loneliness that accompanies AD and narratives in digital spaces creating communities certainly would help them out of loneliness. Wendy Mitchell's blogs serve as a platform for her to record her memories of daily life with AD, while creating a community of readers and followers to understand her journey. In the introduction to her blogs she says, "If anyone chooses to follow my ramblings, it will serve as a way of raising awareness". Although she has been a part of several conferences and discussions on AD all over the country, these blogs serve as a daily documentation of her life from her perspective. She posts a blog almost every day to document her life events, prompting not only awareness but also conversations around the reality of AD rather than science-induced ideas or assumptions by story writers.

Bridging gaps in accessibility

Digital spaces play a pivotal role in bridging the gap between physically accessible and inaccessible spaces. Traditional spaces have proven to be exclusive and difficult to navigate and digital spaces provide opportunities to participate in social, cultural and intellectual activities from the familiar spaces of their homes. Through Mitchell's autobiographical works and blogs, it is evident that she has been accessing physical spaces to feel a sense of normalcy. However, on days when she is unable to navigate these spaces, she uses her blogs to connect with the global community of people she has gathered through the blogs. This digital presence allows her to mitigate feelings of isolation and provides a sense of belonging. **Digital spaces and narrative possibilities**

Mitchell's blogs are dominant with pictures from her daily life. The inclusion of pictures and other images help the readers view the world from her perspective, and they offer a more nuanced and empathetic under-

standing of the condition. As she includes the images, she includes captions describing the moment she clicked them and the reason behind her noticing the objects in the images. In the blog titled 'Back to the Sea', she explains how her camera stopped working and she was forced to navigate the physical spaces without clicking images. She says, "Over those few days, I felt lost without my camera, totally lost. To go out walking with my phone just wasn't the same even though it takes good photos...but it wasn't the same. I felt like a friend was missing...a very good friend. I worried about forgetting..." This shows that she used pictures as a way to remember and recollect her actions through the day so that she could narrate it to her audience. This makes one wonder about the process she followed while writing the three autobiographical books. The multimedia approach to narration in digital spaces allows for a richer experience and conveys the complexity of AD, including the practical challenges of daily life, both emotional and psychological. Digital storytelling surpasses the traditional text-based narratives in terms of capturing the multifaceted nature of the disease.

Interaction on digital platforms

Digital platforms have open comment sections, live chats, and forums of discussions. Interactions through these enable real-time engagement between the audience and the authors. Such interactions can provide immediate support, feedback, and solidarity, creating dynamic exchange of perspectives and experiences. These online communities have become a platform to connect with other individuals who are either caretakers of dementia patients or those who go through the dementia journey themselves, fostering a sense of community and mutual understanding. In Mitchell's blog pages, one finds several comments from nurses and caretakers. One of them by Tannis Esrey reads, "I am a healthcare aide at a personal care home in Canada. I work in the dementia unit. I plan to share your book with many people there and hope it helps some to understand who these people truly are that we spend so much time with and what they have already been through on their journey". This proves that the sense of community is not only built with other patients but also with healthcare workers and other able-minded people. This is crucial in erasing the stereotypes around AD and removing the ableist gaze on dementia in general.

Blurring inside and outside spaces

Zimmermann points out authors like Arthur W. Frank, Howard Brody and Jerome Bruner talk of AD and dementia in the context of "dysnar-

rativia" (9), where personhood and identity do not exist. She deduces the idea of narratives in dementia and claims that "a dedicated consideration of the patient's own as compared to the caregiver's world and word is necessary" (11). This is the primary reason for anyone to read autobiographical writings in AD rather than medical and caregiver accounts. This study by no means undermines those narratives, but the reality of living with AD comes from those who live the Alzheimer's life. Digital spaces like blogs and social media also allow one to upload pictures and communicate beyond words. As seen in the study by Robinson and Johnson, pictures speak volumes.

In Mitchell's blogs, the numerous pictures accompanying her writings show the world through her eyes. The pictures on her daily adventures also serve as a way to recollect the day's happenings as she compiles them in her blogs. Her separate 'gallery' gives the readers a background of her life and those in her life, including her daughters and her beloved pets. As one sifts through these pictures, they allow one to place them in the right context in her blogs, which include more pictures of her daily life.

Her active presence on Twitter also gives one a sneak peek into her everyday life and promotes her blogs and books. She has currently published three books, one as recent as June 2023. In her first book *Somebody I Used to Know*, she mentions, "Now, whenever I feel the pinch of loneliness, I open Twitter and talk to my virtual friends all around the world. Twitter brings the outside world back in" (197). Foucault's concept of outside space in his discussions on 'heterotopia' included the political, national and international lives (*Of Other Spaces*, 1966). It was not until the contemporary criticism of spaces that the outside and inside were integrated in a participative sense. However, digital spaces and their contribution for this integration is not much spoken about. In Mitchell's case, it is obvious that it is her way of dealing with loneliness while connecting with the political, national, and international issues mentioned by Foucault. Her tweets remain politically relevant as she shares some of the work done as part of her dementia volunteering. She also shares personal incidents like the launch of her book and her daily life in some cases. On May 31, 2023, since the power of Twitter changed hands, she tweeted, "It is very sad - since the powers of twitter decided that we could no longer see the feed of those we followed that so fewer people see my tweets now as you have to physically look for them. It also means I don't remember who I am not seeing. It feels like a lonelier place". This tweet is testament to digital spaces giving people with dementia the access to the outside world through their own eyes and that of others. When this access is cut off or limited,

it is no different from how they feel in the outside world. Mitchell, in her book, says, "Dementia can be a lonely world to live in" (130). This is also reflected in her early years of diagnosis when she tries to find a support group of people with early onset of AD but finds only old people. In her words, "None of these people look like me" (29) and the quest continues until she finds videos of Keith Oliver where he documents his life with early onset and progression of dementia.

Digital Divide

Oliver's use of the digital space also brings one's attention to the privilege of access to technology and the ability to use them during their cognitive decline. Mitchell's blog refers to this clearly and she states, "I can type as though dementia never entered my world as that part of my brain has not yet been affected, but that often works against me as people question my diagnosis". The idea of what constitutes Alzheimer's experience is determined by the ableist gaze, thereby placing those who do not fit the narrative at a major disadvantage. It went to the extent where Mitchell lost her financial support for dementia from the government.

Catherine Talbot et al., studied the usage of twitter by people with dementia, under the concept of 'Nothing about us without us', which has been the slogan of all marginalized sectors in the world. The study inquires eleven accounts of people with

dementia under six themes, one of them being 'Stories of Dementia', which follows their personal stories. While the other themes were identified only in selected accounts, all the accounts shared personal experiences of living with dementia. "The findings of this study suggest that people with dementia are using twitter to become visible and broadcast an activist and positive perspective on living with dementia to a wider audience" (116). The study also insists on the free availability of social media "may provide a more equitable path to advocacy and narrative" (112). It must be acknowledged that Mitchell's ability to continue typing and documenting her experiences has been used in the best possible way beyond just her autobiographical books.

Preserving Identity

Any personal documentation revolves around maintaining one's identity as they perceive it to be. AD does not take away one's identity, but society collectively labels them as disoriented and unstable people. Lennard Da-

vis divides disability studies into three models namely the ancient model, the medical model and the social constructionist model (*The Disability Studies Reader*, 2016). As the field of medicine gave life to people with life altering deformities, those with disabilities were identified by the medical terms. For instance, the person with Down Syndrome, the AIDS sufferer, the retard, etc., became a common way to address people with disabilities, thereby placing their identities in their disabilities and not as individuals (Davis, 2016).

Placing this in the context of AD, several caregiver accounts show that their perception of a person with AD is nowhere close to identifying them as an adult with cognitive decline. For instance, Annie Ernaux looks at her mother as a child and says, "I help to take off her panties and put them back on. A child. Period" (*I Remain in Darkness*, 1999, p 53). Autobiographies often address this as they discuss a sense of losing their selves as their cognitive decline progresses. This is evident in Mitchell's autobiography where there are persistent dialogues with her younger self, to whom she does not relate now. She says, "When did you decide that I was to live a different life without all the bits that made me me?" (45). However, she asserts later that she is still herself, "Still me with a diseased brain" (100). Mitchell utters this statement in view of losing friends after her diagnosis. The ableist gaze on the identity of people with AD or any disability in general has dictated how one's self is determined based on their (dis)ability to be a part of the majority while also impacting people's decision to cut off relationships with those diagnosed.

Evelyn Jimmy in her research on Mitchell's blogs acknowledges that her blogs serve as a way to show dementia patients as thinkers and writers, which may otherwise be unnoticed. "Reading Wendy's blogs also made me think about what literacy is to a blog author like her, and how her literacy practices and understanding of its purposes might be altered as she changes, both cognitively and as an author" (56). It is not often that they are recognized as authors, let alone thinkers. The complex process of writing, especially writing blogs which rely on recent memory is a way for them to tell how they do not let AD define who they are.

Conclusion

Digital spaces allow the patients to fill the gaps such as loneliness, disconnect from the outside world, lack of community support that are mentioned in autobiographies.

Aspects such as writing to create awareness, be a voice for herself and others diagnosed with AD while asserting that everyone's experience is different, communicating to a large audience, creating their narratives to break stereotypes around AD are the common factors in Mitchell's autobiographies and blogs. However, digital narratives via blogs and social media have allowed her to frequently and almost immediately update her followers on her daily life and activities. It is also to be noted that her audience comprises not only people with AD but caregivers, and a general audience who are curious about life with AD. This reduces the requirement of privilege to publish a book in order to voice out the everyday experiences of patients living with AD. These digital narratives also have allowed her to create a community of people and interact with a global audience. Although the effort to recall her day and put them into words remains the same, turning narrative into an everyday routine keeps her brain more active and stimulated, which is helpful in dealing with cognitive decline. Blogs and social media narratives are not only extensions of autobiographical books, but also fill the gaps left by the enormous amount of time and effort that go into publishing a book.

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