

ECHOES OF MEMORY: RETROGENESIS AND THE TRANSFORMATION OF IDENTITY IN “STILL ALICE”

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Abstract

Literature, life and society are inseparable. The genre of serious fiction best reveals the interconnectedness of literature with life and society. The paper attempts to throw light on Alzheimer's disease and the vitality of intact memory through the novel 'Still Alice' by Lisa Genova. Viewing the concept of retrogenesis especially focussing on the linguistic, cognitive, behavioural and physical changes through the protagonist, paves way for approaching a disease with a literary perspective. This research also aims to create awareness, a sense of empathy and provide a humanistic approach.

Keywords: *serious fiction, alzheimer's disease, still alice, retrogenesis, awareness and empathy.*

Literature is the artful weaving of words into a tapestry of thoughts and emotions, capturing the essence of the human experience. It transcends mere communication, breathing life into ideas, dreams, and truths that vibrate across time and culture. Through the experimentation of narrative, poetry, and drama, literature invites readers to explore the depths of imagination and the complexity of existence, offering a mirror to society and a window to the soul. It dances between the tangible and the ephemeral, illuminating the intricacies of love, loss, identity, quest, joy, and despair, while challenging the boundaries of reality and inspiring profound reflection. In its myriad forms, literature is both a refuge and a revelation, a testament to the enduring power of language to transform, connect, empathise and transcend.

Among the numerous genres present, serious fiction is a genre of literature that prioritizes depth, complexity, and the exploration of significant themes, often delving into the human condition, moral dilemmas, and social issues. Unlike genre fiction, which often focuses on entertainment and plot-driven narratives, serious fiction aims to provoke thought and introspection, encouraging readers to reflect on their own lives and societal norms. It typically features

well-developed characters, intricate plots, and a nuanced portrayal of emotions and relationships. By engaging with important subjects such as love, loss, identity, and morality, serious fiction seeks to illuminate the complexities of life and challenge readers to confront difficult truths about existence.

The researcher has chosen a serious fiction "Still Alice" by Lisa Genova. It is a poignant novel that explores the life of Alice Howland, a 50-year-old cognitive psychology professor at Harvard, who is diagnosed with early-onset Alzheimer's disease (AD). As Alice grapples with the gradual loss of her memory and cognitive abilities, the narrative delves into her relationships with her husband, children, and friends, highlighting the emotional and psychological impact of the disease on her identity and her loved ones. The novel presents a nuanced portrayal of Alzheimer's, capturing the fear, frustration, and vulnerability that accompany the diagnosis. Through Alice's experiences, the story examines themes of self, the fragility of memory, and the struggle to maintain one's sense of self in the face of a debilitating illness. Genova's compassionate and insightful writing invites readers to consider the profound implications of Alzheimer's, not only

on the individual suffering from the disease but also on the family and community surrounding them. Ultimately, "Still Alice" serves as a powerful reminder of resilience, love, and the enduring desire to connect, even as the mind begins to fade.

Memory serves as the vital thread that weaves together the tapestry of our identities, anchoring us to our past and shaping our present. It holds the stories of our lives, fostering connections with loved ones and preserving shared experiences. When an individual experiences memory loss, the very essence of who they are can begin to unravel, leading to confusion and a profound sense of disconnection. This deterioration not only affects the individual but ripples through their family, invoking feelings of grief, frustration, and helplessness. Loved ones may struggle to reconcile the person they once knew with the unfamiliarity of their current state, creating an emotional chasm that can strain relationships and foster a profound sense of loss. In this way, memory is both a personal anchor and a familial bond, highlighting the delicate interplay between individual identity and collective experience. The protagonist Alice Howland too experiences the consequences of memory loss which obviously hinders her life. She suffers from Alzheimer's a neuro-degenerative disorder.

Alzheimer's disease is a progressive neurological disorder that primarily affects memory, thinking, and behaviour. It is the most common cause of dementia, characterized by the gradual decline of cognitive functions. Individuals with Alzheimer's often experience difficulty remembering recent events or learning new information, while older memories may remain intact in the early stages. As the disease progresses, it leads to confusion, impaired judgment, and difficulty with language and reasoning. People may exhibit changes in personality, mood swings, and may become withdrawn or agitated. Alzheimer's is associated with the building up of amyloid plaques and tau tangles in the brain, disrupting communication between neurons and leading to cell death. The disease typically progresses through three stages-mild, moderate, and severe-each with increasing levels of cognitive impairment and loss of independence. Currently, there is no cure for Alzheimer's, but treatments

are available to help manage symptoms and improve quality of life for affected individuals. Early diagnosis and intervention can be beneficial in managing the disease's impact.

Barry Reisberg is the first name that comes to the mind when the talk of memory and Alzheimer's is taken into consideration. Barry Reisberg over the past three decades has directed research that has significantly advanced the understanding and treatment of Alzheimer's disease. He was the first to describe many crucial symptoms and the characteristic clinical course of the disease. His clinical staging measures, including the Functional Assessment Staging measure and the Global Deterioration Scale (GDS) are mandated throughout the United States and in parts of Canada and Europe, and are recommended in Japan and Australia. He played a key role in the development of all three major pharmacological approaches to treating Alzheimer's disease. His work on retrogenesis has advanced the understanding of disease management and provided insights into the disease. He has received numerous grants and awards, including a Lifetime Achievement Award from the Alzheimer's Association. Currently, he serves as the emeritus director of the clinical core of the Alzheimer's disease Center, clinical director of the Aging and Dementia Research Center, and as a professor of psychiatry at NYU School of Medicine. Additionally, he is an adjunct professor at McGill University's Faculty of Medicine in Montreal.

The concept of retrogenesis, developed by Barry Reisberg, refers to the reverse developmental process observed in individuals with Alzheimer's disease and other forms of dementia. According to this idea, as cognitive functions decline, individuals regress through the stages of cognitive and emotional development, akin to the way a child matures. This regression can manifest in various ways, such as a diminished ability to perform complex tasks and a return to more primitive behaviours. For instance, individuals may revert to simpler thought processes, loss of language skills, and a diminished capacity for social interactions, reflecting earlier stages of human development. Reisberg posits that this process can help caregivers and medical professionals understand the changing needs and behaviours of individuals with

dementia, enabling them to provide more compassionate and effective support tailored to the individual's current abilities and developmental stage. Retrogenesis highlights the importance of recognizing the emotional and psychological aspects of dementia, emphasizing that the individual retains a history and identity that should be honoured, even as their cognitive functions decline.

Barry Reisberg's framework consisting of Seven Stages of Alzheimer's helps to illuminate the changes in the abilities of individuals with the disease, recognizing that experiences vary among each individual. In Stage one, there is no impairment; individuals do not face memory issues, and medical professionals find no dementia symptoms. Stage two involves very mild cognitive decline, where the person senses occasional memory lapses, yet no dementia is detectable to others or through medical evaluation. In Stage three, mild cognitive decline becomes evident, as friends and family notice difficulties such as trouble recalling names, finding the right words, and managing tasks in social or work environments. Stage four marks moderate cognitive decline, where forgetfulness of recent events, challenges with complex tasks, and emotional withdrawal are identifiable during medical interviews. By Stage five, moderately severe cognitive decline leads to noticeable memory gaps, requiring assistance with daily tasks, with individuals sometimes unable to recall personal information like their address or education while still recognizing significant details about themselves and their families. In Stage six, severe cognitive decline is apparent, with further memory loss, personality changes, and a need for extensive help with daily activities. Individuals may forget recent experiences, struggle with personal history, and have difficulties with daily life, including dressing and controlling bodily functions. Finally, Stage seven represents very severe cognitive decline, where individuals lose their ability to respond to their environment, converse, and control movement. They may utter a few words or phrases but require assistance with personal care, such as eating and personal hygiene. At this stage, they often lose the capacity to smile, sit unsupported, or hold their heads up, exhibiting abnormal reflexes, rigid muscles, and impaired swallowing.

The paper attempts to throw light on the how Alice travels through the stages of AD taking the physical, cognitive, linguistic and behavioural changes she undergoes into consideration. The novel "Still Alice" depicts Alice Howland's journey through Alzheimer's disease through various incidents that align with the stages of the condition. Alice is a successful cognitive psychologist, attending lectures and engaging in her work. She has always been a victorious professional, a loving mother and a dutiful wife.

There are no noticeable symptoms of Alzheimer's initially. There is not a trace of evidence that reveal her internal memory destruction which imply the stage one or the no impairment stage. In the stage two or the very mild decline stage, Alice starts to notice occasional forgetfulness, like misplacing items or having trouble recalling names. This is often dismissed by Alice by relating it to normal aging, multi-tasking, busy professional schedules and as menopausal symptoms. Her first encounter with AD was when she searched for her blackberry charger and finally gives up by getting a new one. Later on she even places her mobile into the refrigerator and brought to awareness only when her husband John finds it.

"She simply couldn't find the word. She had a loose sense for what she wanted to say, but the word itself eluded her. Gone. She didn't know the first letter or what the word sounded like or how many syllables it had." (Genova11)

The above incident reveals her sudden forgetfulness of a word during her lecture. However, she dismisses it as the effect of the drink she had earlier. This quote elucidates the indication of linguistic decline taking place in Alice. It hints her foldaway into the second stage commonly known as very mild decline stage.

The mild decline stage is the third level on scale. It is a vital stage where an individual exercise notable multiple changes on a large scale. Alice experiences more visible memory lapses, such as difficulty finding the right words during conversations, getting lost in familiar routes and struggles to remember recent events. Her family begins to notice these changes. After a dinner with her daughter Lydia, she had forgotten to take her blackberry from the

table. As soon as the waiter handed it over to her that she realised the act she has performed. The deed done by Alice at the hotel made Lydia a little aware of the recent absent mindedness of her mother. Getting lost in familiar route is dominant in this stage. Alice is no exception. The following quote would be a sufficient proof disclosing the decline in her cognitive ability.

"She wanted to continue walking but stood frozen instead. She didn't know where she was...She knew she was in Harvard Square, but she didn't know which way was home."(Genova24)

The moderate decline or the fourth stage is an important stage where the person may face difficulties in doing complex tasks, experience mood swings leading to withdrawal and denial. They might become less aware of current events and of personal history. Alice's condition becomes more apparent. She occasionally forgets significant details, like her children's names, and has difficulty with complex tasks. She can still mask her symptoms in social situations but becomes increasingly aware of her decline.

"She wouldn't fly across the country without him, and she'd have to make up some excuse. Fearful of getting lost or confused far from home, she'd been avoiding travel. She'd declined an offer to speak at Duke University next month and thrown out the registration material for a language conference she'd attended every year since she was a graduate student." (Genova 106)

The above quote justifies her gradual unwillingness in social participations. She has confined herself into a cocoon avoiding contact with the world around her. She even rejects joining regular get-together with friends so as to avoid unexpected embarrassments. She is found moody most of the time and this shows the behavioural changes in Alice and of her obvious social withdrawal.

The stage five or the moderately severe decline stage is a very crucial stage. A lot of support system would be needed. The person may have difficulty recalling major events, weather, and current address. They are prone to have confusion over time and place and might become dependent on a person for personal assistance. Alice finds it hard to hold on to her personal information, depends on

her family members for her daily living and mostly unaware of personal grooming. Her moments of confusions and struggles become frequent leading to distress. The below quote shows the pathetic condition of Alice and making one realise the requirement of intense caretaking.

"She lost a little of her confidence and status when she brushed her teeth with a moisturizer. She lost a bit more when she tried all morning to call John with the television remote control. She lost the last of it when her own unpleasant body odour informed her that she hadn't bathed in days, but she couldn't muster up the courage or knowledge she needed to step into the tub."(Genova 287)

Alice forgetting that Lydia is the very actress who performed onstage brilliantly, she appreciates and questions her about her whereabouts. Lydia is pained to see her mother in such a state. She couldn't recognise her daughter. Once Alice even battle with a piece of clothing not knowing how to put them on and then John comes to her rescue. This incident gives a comprehension of the aid needed for personal assistance in everyday life be it simple or complex.

The severe cognitive decline stage or the sixth stage is an advanced stage similar to the fifth one. The person is likely to confuse family members with others, even simple tasks would seem herculean, personality changes, feeling of isolation, hallucination, and frustration and suspicion are common in this stage. They might sleep more and tend to wander and get lost.

"The mail had just been delivered through the slot in the door, and it lay on top of the hole, somehow hovering there." (Genova 232)

Alice mistakes the doormat to a hole in the ground. Auditory and visual hallucinations were realities of people with AD. Once she even suspects that a thief had broken into their house which reveals the feeling of suspicion, a common symptom of this stage. The very severe AD is the final seven stage of the disease. It is a wretched state where the person undergoes physical decline. Their body becomes rigid and speech becomes limited to words or mere nods. They become unresponsive to the environment and absolute care is needed. They would find difficulty in chewing and swallowing, develop parallel side effects and

will lead to eventual death. Alice fortunately does not run that far into the disease and Lisa Genova has ended the novel with a positive note.

Thus, Reading a literary work, such as a novel that explores medical conditions, fosters empathy and humanitarian feelings in ways that reading a medical book often cannot achieve. In a novel, the characters' personal stories and experiences provide a narrative that humanizes the realities of living with a disease. Through rich, emotional storytelling, readers are invited to step into the shoes of these characters, experiencing their struggles, fears, and triumphs. This immersive experience cultivates a deeper understanding of the emotional and psychological impact of illness, which can be overlooked in clinical discussions.

Moreover, novels often explore the social implications of disease, shedding light on the stigma, isolation, and challenges faced by individuals and their loved ones. This broader context encourages readers to appreciate the multifaceted nature of health issues, prompting them to consider not just the biological aspects, but also the emotional and societal dimensions. In contrast, medical books typically focus on facts, symptoms, and treatments, which may provide valuable information but often lack the narrative and emotional depth necessary to inspire genuine empathy. By engaging with the lived experiences depicted in fiction, readers can develop a more compassionate perspective towards those affected by illness. This emotional engagement can lead to increased awareness and advocacy for better understanding, support, and treatment of these conditions. Ultimately, literature serves as a powerful tool for fostering empathy; as it highlights our shared humanity and the profound ways in which diseases intersect with our lives, making it an

essential complement to the more detached approach of medical literature. The paper has attempted to lucidly elaborate on the concept of retrogenesis by Barry Reisberg and of the various changes it causes on a person affected by Alzheimer's by citing quotes and incidents from the life of the protagonist Alice from the novel *Still Alice*. The paper creates an awareness of a decisive disease with the aid of literature, where memory lapses should no longer be taken for granted.

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