

Still Alice: Understanding the Representation of Alzheimer's Disease in Media

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Abstract: Dementia is a common neurodegenerative disease that primarily affects the aging population. The disease is characterized by a decline in cognitive skills that impact communication, memory, and sometimes physical abilities. Past research indicates that these changes impact communication and relationships between those with dementia and their family members; furthermore, research indicates that media representation of the illness contributes to a societal stigma and fear of dementia that can make the illness harder to deal with. The purpose of this critical analysis is to examine how the 2014 movie, *Still Alice*, highlights changes in communication and relationships and determine in what ways it adheres to or subverts common stigmatizing frames found in existing dementia media research. This study found that *Still Alice* portrayed significant changes in Alice's communication and memory that ultimately impacted her familial relationships and self-identity. Many of these changes were negative, thus reinforcing the negative stigma surrounding the illness, but the portrayal of positive changes in Alice's relationship with her youngest daughter provides a counter-frame that can work to show people that not all the changes associated with dementia are negative.

Introduction

Dementia is a common neurodegenerative disease that primarily affects aging individuals. Dementia, specifically Alzheimer's disease—the most common type of dementia—negatively affects the mental and physical processes that are necessary for the motor, memory, decision-making, and communication skills that people use daily. The adverse effects on communication include difficulty recalling words, understanding semantics, and comprehending others.¹ Additionally, the general decline in critical abilities frequently causes individuals to become gradually more dependent on family members for anything from simple daily tasks to making important medical decisions. These challenges affect communication and change pre-existing roles within the interpersonal relationships between individuals with dementia and their family members. However, dementia patients and their family members are not just faced with changes in their communication and relationships, they are also faced with a stigma that stems largely from negative media representation of the illness.

Literature Review

Dementia is a communication-debilitating illness (CDI), meaning that it affects the individual's ability to communicate as effortlessly as they did before they started to experience symptoms. Those who experience CDIs report experiencing a decrease in the number of people they communicate and hold interpersonal relationships with because of these changes.² Similarly, in a study on perceived communication changes between those with dementia and a family member, those with dementia reported that communication in their close interpersonal

¹ Aimee E. Miller-Ott, "Just a Heads Up, My Father Has Alzheimer's": Changes in Communication and Identity of Adult Children of Parents with Alzheimer's Disease," *Health Communication* 35, no. 1 (2020): 119, <https://doi.org/10.1080/10410236.2018.1547676>; Mansoureh Nickbakht et al., "Putting 'the Broken Bits Together': A Qualitative Exploration of the Impact of Communication Changes in Dementia," *Journal of Communication Disorders* 101 (2023): 1-2, <https://doi.org/10.1016/j.jcomdis.2022.106294>.

² Jennifer J. Bute et al., "Effects of Communication-Debilitating Illnesses and Injuries on Close Relationships: A Relational Maintenance Perspective," *Health Communication* 21, no. 3 (2007), <https://doi.org/10.1080/10410230701307675>

relationships had been negatively impacted, both in quantity and quality of conversations. Further, dementia patients openly expressed that communication had become difficult due to losing the skills associated with word retrieval and understanding meaning. As a result, patients expressed the frustrations they felt at not being able to communicate as they used to and with feeling judged by others. They realized that sometimes how they behave or communicate may not make sense to those around them, making it easy for them to feel misunderstood, embarrassed, and even disrespected. However, many patients found that disclosing their dementia to others helps mitigate these feelings.³ Therefore, dementia patients understand that dementia is limiting their communication abilities, thus impacting their relationships, yet some patients have found ways to adjust to these changes.

Studies on family perspectives indicate a similar belief that family communication and their relationship with the dementia patient have changed since the onset of symptoms. In the same study by Mansoureh Nickbakht et al., family caregivers of individuals with dementia noted that the patient sometimes uses the wrong words or is otherwise incoherent.⁴ They also noticed a connection between decreased memory and communication abilities whereby the patient will repeat the same questions or stories. In a study by Aimee Miller-Ott that was focused on adult children of Alzheimer's patients, children expressed that even though technically they are still their parent, the topics and manner of communication are different than what they were before the illness. They felt that they essentially became a parent to their own parent, especially when they must correct their parent's behavior or speak on their behalf in a public or healthcare setting. These changes are often frustrating and overwhelming for adult children of Alzheimer's patients.⁵ However, in a different study, Jennifer Bute and others explained that while many

³ Nickbakht et al., "Putting 'the Broken Bits Together,'" 5-8.

⁴ Nickbakht et al., 6.

⁵ Miller-Ott, "Just a Heads Up," 4-6.

participants in their study on CDI expressed the same feelings of frustration and stress explained in Miller-Ott's research, some found helping the individual with the CDI rewarding and were able to appreciate the new relationship they established.⁶ In other words, despite participants' agreement that there are at least some changes in their communication and relationship after the onset of a CDI, there are some differing experiences and opinions about whether the changes are positive or negative.

These changes in communication and cognitive abilities that characterize dementia largely contribute to the general stigma surrounding this illness.⁷ Johnson et al. found that the stigmatizing behaviors of pity, social avoidance/distancing, and discrimination are most strongly associated with a perceived worsening prognosis of difficulties speaking, completing their normal tasks, and maintaining their appearance or hygiene.⁸ In two separate studies, researchers explored how media representations of dementia and Alzheimer's contribute to this stigma and fear of the illness's symptoms. For example, Flemish children's books utilize metaphors about the illness to describe the patient's perceptions of their illness and the family member's perceptions of the patient's symptoms. The most notable of these metaphors is the comparison to family members with dementia as children and as "gone".⁹ In their study on various forms of Belgian media, Van Gorp and Vercruyssen identified common framing themes, including: dementia is a slow death that leaves the body as an "empty shell" with no identity, that there is

⁶ Bute et al., "Effects of Communication-Debilitating Illnesses," 4-10.

⁷ Silke Creten and Priscilla Heynderickx, "Dementia, or Lazy Gnomes Lost in the Dark? The Metaphorical Representation of Dementia in Children's Books," *International Journal of Language Studies* 17, no. 4 (2023).; Rebecca Johnson et al., "The Relative Contributions of Disease Label and Disease Prognosis to Alzheimer's Stigma: A Vignette-Based Experiment," *Social Science and Medicine* 143 (2015), <https://doi.org/10.1016/j.socscimed.2015.08.031>.; Baldwin Van Gorp and Tom Vercruyssen, "Frames and Counter-Frames Giving Meaning to Dementia: A Framing Analysis of Media Content," *Social Science and Medicine* 74, no. 8 (2012), <https://doi.org/10.1016/j.socscimed.2011.12.045>.; Wenqian Xu, "The Stigma of Dementia and the Media: An Analysis of Reality Shows about Older People with Dementia Running a Pop-Up Restaurant," *Journal of Aging Studies* 59 Dec (2021), <https://doi.org/10.1016/j.jaging.2021.100967>.

⁸ Johnson et al., "The Relative Contributions of Disease Label."

⁹ Creten and Heynderickx, "Dementia, or Lazy Gnomes," 47-49.

still hope for a cure, and that patients become children to their own children who must take care of them.¹⁰

There are similarities between these stigmatizing thoughts and the real behaviors and feelings expressed by patients and family caregivers in Miller-Ott and Nickbakht et al.'s studies, like patients becoming children once again. This indicates that this stigma may contribute to fears of being judged or misunderstood and negative perceptions of their illness. Even though some of these stigmatizing representations may portray the illness accurately, it is critical for media representations of dementia to intentionally create counter-frames by including more positive ideas or images of people living normally with the illness, as this can be possible with some forms of dementia. This can include reframing dementia as a more natural part of aging; highlighting that while being a family caregiver has many challenges, it can bring family members back together in a more meaningful way; and showing dementia patients' continued engagement in communication and social roles, even if it is more challenging or seems more difficult at times.¹¹

Still Alice

The 2014 movie, *Still Alice*, based on the book by Lisa Genova, follows Dr. Alice Howland, a linguistics professor who is diagnosed with familial early-onset Alzheimer's shortly after her 50th birthday. At the beginning of the movie, she was frequently referred to as highly intelligent by her husband, children, and colleagues. Despite her mostly successful efforts to hide her memory lapses from those around her, the audience begins to see that she is having difficulty remembering small things and has been getting lost. For example, while presenting her research at UCLA, she forgot her speech and blamed it on having too much champagne earlier that day.

¹⁰ Van Gorp and Vercruyssen, "Frames and Counter-Frames."

¹¹ Van Gorp and Vercruyssen.; Xu, "The Stigma of Dementia."

Alice secretly went to the neurologist, and after ruling out a head injury, stress, depression, and lack of sleep, the doctor ran memory tests and an MRI. The physical results came back normal, but the memory tests indicated that she may be in the early stages of Alzheimer's disease, despite being much younger than the typical dementia patient.

During her diagnosis process, she finally told her husband about the symptoms she was experiencing and that the doctors believe she may have early-onset Alzheimer's disease. At first, her husband, John, did not believe her because he had not noticed any changes in her cognitive abilities, saying that it is normal to forget things sometimes. However, Alice's fear of this potential diagnosis finally reached the breaking point during this conversation, as she said through sobs, "It's like something just drop-drops out under me... It feels like my brain is [profanity] dying and everything I've worked for in my entire life is going. It's all-all going."¹² After officially being diagnosed, she broke the news to her three kids. The kids had varying reactions: Anna, the oldest, was very emotional; Tom, the middle child, wanted to know about treatment options; and Lydia, the youngest, was calm because she had noticed some of Alice's memory lapses in recent months.

In the early stages of her illness, she attempted to continue her normal daily activities, with her main challenges being word retrieval or doing small things incorrectly, like putting shampoo in the refrigerator. While she initially continued teaching, her declining ability to remember her lesson plans led to negative course reviews from students who all seemed to feel that even she did not understand the material. Once her symptoms became more imposing on her daily life, she created a document with personal questions that she would answer each day. The document directed her to watch a video if she could not answer the questions. In the video, she

¹² *Still Alice*, directed by Richmond Glatzer and Wash Westmoreland (Sony Pictures Classics, 2014): 00:23:34.

told her future self to swallow a whole container of sleeping pills that she had hidden. She also began to address her increasingly impending mortality and her worsening prognosis. While visiting her childhood beach house, she expressed her hope that John would take a sabbatical so that they could spend their last year together with her as “herself” and she compared her life to the short lives her mom and sister led, as they both also passed away at an early age.

Her symptoms began to progress increasingly rapidly. For example, when she and her husband had plans, she was distracted as she got ready, couldn’t locate the bathroom, had an accident, and then cried because she didn’t know where she was. Though she was struggling cognitively, she was able to work past her symptoms to present at an Alzheimer’s Association event. In this speech, she succinctly described her feelings toward her illness:

All my life, I’ve accumulated memories. They’ve become, in a way, my most precious possessions... everything I accumulated in life, everything I’ve worked so hard for, now all that is being ripped away. As you can imagine, or as you know, this is Hell. But it gets worse. Who can take us seriously when we are so far from who we once were? Our strange behavior and fumbled sentences changed other’s perceptions of us and our perception of ourselves. We become ridiculous, incapable, comic. But this is not who we are. This is our disease, and like any disease it has a cause, it has a progression, and it could have a cure...¹³

However, the clearest shift into the later stages of Alice’s symptom progression occurred not long after this speech, when she could not recognize Lydia after watching her act in a play. Her family, aside from Lydia, became uncertain of how much information to tell her out of concern for making her remember things that weren’t necessary. Furthermore, rather than the sabbatical that she was hoping for, her husband accepted a new job offer, causing Alice to realize that he did not want to stay at home and watch her decline. She had a caretaker, as she could no longer be alone, and Lydia moved home when John moved for his new job. By the end of the movie,

¹³ Glatzer and Westmoreland, *Still Alice*, 1:07:19.

Alice became almost entirely dependent on Lydia and seemed to have lost much of her ability to speak.

Discussion

The purpose of this analysis is not to determine the accuracy of this portrayal, as I am not a qualified medical professional. Rather, this study is to understand how *Still Alice* highlights changes in communication and relationships and examine the ways it adheres to or subverts the common stigmatizing framing in representations of dementia as found in my literature review. Alice clearly struggled emotionally with losing her memory and communication abilities, as those had been highly important to her identity. Her plan to overdose on sleeping pills once she lost her important memories showed that she felt that living with her symptoms would be worse than death. Thus, in line with existing research, Alice herself frames her illness as taking away her identity.¹⁴ She also expressed feeling a stigma about her illness, both in her speech and to her husband shortly after her diagnosis, saying, “I wish I had cancer... No, I do. I mean it. I mean, I wouldn’t feel so ashamed. When people have cancer they wear pink ribbons for you, and go on long walks, and raise money, and you don’t have to feel like some kind of a—I can’t remember the word.”¹⁵ She also mentioned the common framing theme of hope for a cure during her speech, as shown in the quote above.¹⁶ Even though she mentions a few times that she has good days where she knows who she is and what she is doing, the portrayal of a generally rapid decline in cognitive and self-care abilities likely reemphasizes the stigma associated with a poor prognosis.¹⁷

¹⁴ Van Gorp and Vercruyssen, “Frames and Counter-Frames.”

¹⁵ Glatzer and Westmoreland, *Still Alice*, 00:36:27.

¹⁶ Van Gorp and Vercruyssen, “Frames and Counter-Frames.”

¹⁷ Johnson et al., “The Relative Contributions of Disease Label.”

Alice's family was unsure how to navigate their changed relationship with her once her symptoms worsened. As mentioned, they kept things from her, like John's decision to accept a job in a different state. This extended even into small things, like whether telling her the details about when and where Lydia's play was would cause undue stress. At the end of the movie, John wonders if she believes she is a child again when referring to her seemingly not knowing where she is. He also says, "It's important to remember who Alice was. She would not want to be a burden."¹⁸ Not only was Alice still alive when he said this, she was in the room. By referring to her in the past tense, it can be inferred that he believed the Alice he once knew was gone, a common metaphor used in dementia representation.¹⁹ Alice's treatment was not a focus of this movie, but there are two instances in which he came to appointments with her and spoke on her behalf, reinforcing the idea that Alice lost her independence. Additionally, John and Lydia both took on the role of being a family caregiver, highlighting the change in relational roles found in families with dementia patients.²⁰

Prior to Alice's diagnosis, Lydia and Alice had a slightly tense relationship. However, Lydia was the only family member who adapted to the changes that came with Alice's Alzheimer's. Their communication became more frequent, and they connected on a more personal level after Alice mistakenly read Lydia's diary. While the rest of the family did not want to bother her with information, almost as if they thought her brain was too fragile, Lydia respected that her mother wished to be told what was going on. Past research highlights that for some individuals, the changes in communication with dementia can create a more positive relationship, as it did with Alice and Lydia.²¹ Despite Lydia having to leave L.A. and put her

¹⁸ Glatzer and Westmoreland, *Still Alice*, 1:20:29.

¹⁹ Creten and Heynderickx, "Dementia, or Lazy Gnomes."

²⁰ Miller-Ott, "Just a Heads Up."; Nickbakht et al., "Putting 'the Broken Bits Together.'"

²¹ Nickbakht et al.; Bute, et al., "Effects of Communication-Debilitating Illnesses."

acting on pause, she acknowledged that being with her mom was what she felt was best. This highlights the potential counter-framing that being a family caregiver can improve family relationships.²²

Conclusion

Dementia and Alzheimer's disease inherently affect communication through the biological processes that affect general cognition. This change in communication abilities prevents dementia patients from maintaining their typical communication habits with family members, which in turn affects their relationships. While dementia can have drastic effects, not all of these are negative or occur for every person with the illness, as the media tends to suggest. By highlighting only negative elements of the illness, and at times belittling those with it, media representations of dementia create a stigma that makes individuals with the illness and their families feel misunderstood or judged. *Still Alice* highlights the changes that individuals with dementia and their families must navigate after diagnosis. The representation of dementia through this movie could contribute to stigmatization by increasing fear about symptoms, but it could also simultaneously increase awareness for this health issue and show how someone with this illness can continue having close relationships, even if they are different than how they used to be. Lydia and Alice's relationship in this movie provides an important counter-frame that can reshape how people expect communication and relationships to change with the onset of dementia, potentially decreasing the stigma that is associated with fear of these changes.

²² Van Gorp and Tom Verduynde, "Frames and Counter-Frames."; Xu, "The Stigma of Dementia."

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