

Alzheimer's Disease and Emotions: An Interpretive Phenomenological Analysis of the Film "Still Alice"

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Abstract

BACKGROUND:

Despite the fact that Alzheimer's disease (AD) afflicts millions of people in the United States, most Americans do not come into contact with anyone who has the disease. Due to this lack of firsthand experience with AD, the general public's understanding about the experiences of individuals living with the disease, and their framework of expectations about it, are often built on social representations—such as films.

OBJECTIVE:

We examined representations of the lived experience of an individual with AD in the film *Still Alice* using qualitative methodology.

METHOD:

The authors applied Interpretive Phenomenological Analysis (IPA), guided by Socio-emotional Adaptation Theory, to the film *Still Alice*. Following multiple careful readings of the film transcript, the

authors observed the film while following the transcript, and finally viewed the film without referring to the transcript. Researchers created a provisional codebook defining overarching and subordinate themes as they emerged throughout the film.

RESULTS:

The experience of living with AD was represented in *Still Alice* by spanning the trajectory from pre-diagnosis through late-stage dementia. Overarching themes (and subordinate themes) emerged as the film progressed. They included:

- Premorbid Context and Foreshadowing (Familial Relationships; Self-concept)
- Questioning Identity (Preservation of Self; Shifting Identity)
- Coping and Family Role Shifts (Coping; Changing Caregiver/Family Dynamics)

CONCLUSION:

The film *Still Alice* offers a first-hand representation of the experience of declining cognitive and physical abilities associated with AD. The protagonist's personal struggles with her inevitable decline are interwoven within a complex web of her social relationships and psychosocial resources.

KEYWORDS: Alzheimer's Disease, Emotions, Motion Pictures; Qualitative Research

Introduction

As of 2018, Alzheimer's disease (AD) afflicted an estimated 5.7 million Americans.¹ Yet the general public has little contact with this isolated population,² leading former Surgeon General Dr. David Satcher to call AD "the most under-recognized threat to public health in the 21st century."³ Due to this lack of firsthand experience with AD, the general public's expectations surrounding the disease are often built on social representations, such as those presented in film.⁴

AD DEPICTED IN FILM

The "circuit of culture" is a social theory that offers a lens through which to view and understand these social representations.⁵ In the circuit of culture, language, including that in film, provides representations that produce meaning. These meanings have the potential to influence the way people interact with their environment. Therefore, it is important to understand how AD is represented in film.

A limited number of studies have examined representations of AD in film; however, they are often either simply descriptive, or lack a rigorous methodological approach. Several of these published manuscripts take an editorial position and do not

divulge the methods by which they came to their conclusions.⁶⁻¹⁰ Others identify a method of analysis but do not explain how the method was applied.¹¹ Still, there are patterns that may be gleaned from the existing literature.

In one study, three independent researchers are described as viewing and then scoring 23 films based on the symptoms, capacities, and behaviors associated with AD that were presented in each.¹² The authors concluded that the full range of AD symptoms are typically not represented in film.

In a descriptive study, Segers provided a robust documentation of how AD is described and presented in 24 films. He concluded that AD is rarely mentioned by name in the films, and is instead implied.¹³ In another study, framing analysis was used to review depictions of people with AD in film, newspapers, and literature, and noted that persons with dementia are typically represented in a negative light—as beings without identity.¹⁴ Overwhelmingly, current films tend to distance the viewer from the experience of having AD by focusing on the reactions of caregivers or other characters—ensuring that the experience of AD remains not relatable, and contributing further to the isolation of those with the disease.⁹

A RARE PERSPECTIVE

In contrast, the film *Still Alice* provides a rare cinematic representation of cognitive decline from the perspective of the protagonist.⁷ *Still Alice* has also had an unprecedented reach for a film focusing on dementia, grossing \$43.9 million worldwide.¹⁵

Based on the film's perspective, the purpose of the current study was to examine representations in *Still Alice* of the lived experience of AD through Interpretative Phenomenological Analysis (IPA)

guided by Socio-emotional Adaptation Theory.¹⁶ Socio-emotional Adaptation Theory posits that a combination of psychosocial resources (eg, formal caregiver support, informal caregiver support, self-efficacy, and adaptation) may predispose persons with AD toward various emotional responses. Team members included a gerontologist with expertise in qualitative methods and a doctorally-prepared physical therapist.

Method

The research team conducted an interpretative phenomenological analysis (IPA) of the film *Still Alice* with the intent of gaining a deeper understanding of the relationship between psychosocial factors and emotions presented in the film.¹⁷ IPA has philosophical roots in phenomenology. Phenomenology is a philosophical perspective for discovering and describing how consciousness makes sense of the world around us.¹⁸ Phenomenology, which presents an individual's raw perception of the world prior to any interpretation or analysis, elevates subjectivity as essential for human understanding. In rehabilitation, phenomenology provides clinicians with a first-person account of what it means and what it feels like to live with disability.

Based on phenomenology, IPA involves a descriptive, reflective, interpretive, and engaged mode of inquiry that seeks to understand the essence of experience.¹⁹ The detailed, interpretive analysis involved in IPA is best suited for small samples.²⁰ As such, this research approach is appropriate for gaining a deeper understanding of the lived experience of the protagonist Alice Howland in the film *Still Alice*, as well as her social network, and the meaning they each assign to changing functional status related to Alzheimer's disease.²¹

Data Collection

The authors obtained the original screenplay of *Still Alice* from a free online website (<http://www.simplyscripts.com>). A screenplay provides a 'blueprint' for a film, which is generally followed, but some liberties often are taken and the script is adjusted during filming and production.²² Therefore, the first author of this study carefully edited the *Still Alice* screenplay while watching the film, adjusting the text when needed to ensure it matched the final film product. The second author reviewed the transcribed screenplay to ensure it contained accurate text. Data management was facilitated through NVIVO 11 (QSR International Pty Ltd, London).

Data Analysis

The idiographic nature of IPA involved researchers immersing themselves in the transcript.²³ Following multiple careful readings, each researcher then observed the film—first following along with the transcript, and then without the transcript. During this process, researchers noted voice inflection and cadence along with non-verbal characteristics of the film and actors in the margin of the transcript. Initial notes were made in the left-hand margin of the transcript to summarize content.

CODEBOOK

The authors created a provisional codebook—with codes and definitions both from deductive codes based on the Socio-emotional Adaptation Theory and inductive codes from careful reading of the transcript—for use during the next phase of analysis.¹⁶ (Appendix). The codebook included each of the psychosocial components of the theory (eg, formal

caregiver) along with emotions (eg, depression). During this stage, emergent themes were noted in the right-hand margin of the transcript and added to the codebook. For example, due to the protagonist's use of technology to aid her memory and as a tool for communication, "technology" was added to the codebook. Finally, a list of superordinate themes (eg, premorbid context, questioning identity) was constructed through clustering of themes and the links between them (eg, patient, disengaged) to create the final codebook (Appendix). Resulting superordinate and sub-themes were repeatedly matched to the language and non-verbal cues (eg, actors' behaviors, music, lighting) within the film to ensure they were grounded in the actors' accounts.²⁴

ANALYTICAL RIGOR

The researchers took several steps to ensure analytical rigor, including triangulation and reflexivity.²⁵ First, throughout the analysis phase, each researcher maintained a diary that included personal thoughts and reflections, in order to account for how the researcher's own worldview might influence interpretation of the data.²⁴ Additionally, both authors participated in analysis and interpretation of the data. Inter-rater reliability was evaluated with a Cohen's Kappa statistic using the coding comparison function in NVIVO, with researchers meeting to discuss any discrepancies in coding. Of the 40 codes, 11 did not meet the threshold of at least 80% agreement after the first pass of coding. Researchers reviewed the definitions of these codes and revisited the transcripts separately. Following this second meeting, interrater reliability was assessed and the Cohen's Kappa threshold was verified for all codes. Team members included a gerontologist researcher and a physical therapist. Finally, as the transcript was accessed from a free available website, the researchers viewed the film

while consulting the transcript, and made corrections where appropriate to ensure the text was accurate.

Results

We identified three overarching themes in the film (eg, Premorbid Context and Foreshadowing; Questioning Identity; Coping and Family Role Shifts) along with associated subordinate themes that were nested within each overarching theme (eg, Familial Relationships, Self-concept; Preservation of Self, Shifting Identity; Coping, Changing Caregiver/Family Dynamics).

PREMORBID CONTEXT AND FORESHADOWING

The beginning of the film highlights the premorbid context surrounding Alice Howland's familial relationships and self-identity. These scenes provide foreshadowing of how her psychosocial resources interact with her experience of initial cognitive decline.

SUB-THEME: FAMILIAL RELATIONSHIPS

Alice, 50 years old, is the matriarch of a competitive but close family that values knowledge, intellect, and achievement. Her husband calls her, "The most beautiful and the most intelligent woman I have known in my entire life." Her daughter Anna, son Tom, and husband John are all in traditionally esteemed fields of law, medicine, and science. Her daughter Lydia is the exception—an aspiring actress who lives far away from Alice in California. Several scenes near the beginning of the film depict the Howland family coming together for celebrations and talking often in-person or over the phone. Alice appears to have a particularly close connection with her daughter Anna; they are several times depicted playing a technology-based word game

together.

Alice and John enjoy a marriage with shared intellectual interests and ambitious career pursuits. Alice and Anna share similar personality traits, including a desire for career success and achievement. Lydia, meanwhile, is disconnected from the rest of the family, despite the close nature of the family unit. There are several scenes where Anna disparages Lydia's life choices; Alice attempts to convince Lydia that she should attend college to pursue a more productive career:

ALICE- Lydia, don't you think it's time you reconsidered things? You're so smart. There's so much more you could be doing with your life...

LYDIA- Like going to college?

ALICE- Yes! Yes! Like college.

LYDIA- Yeah. Like we've never talked about that before—every single day of my life. I figured out what I wanted to do and I'm doing it. It's a good thing.

ALICE- But on whose dime?

LYDIA- You're helping Tom with Med school. You helped Anna with law school.

ALICE- Sweetheart...those are real careers. I just don't want you to limit your choices.

Despite their differences, it is clear that Alice and Lydia share a mutual love and respect; however, their differing opinions regarding the definition of success are a source of conflict.

SUB-THEME: SELF-CONCEPT

Alice is a professor of linguistics at an Ivy League university. Her position as an expert in the meaning

and structure of language provides an important backdrop related to her future experience of cognitive decline. She presents herself as confident, articulate, and poised. Alice identifies strongly with her work in linguistics and in teaching. She works at a renowned institution and is on occasion asked to speak nationwide. She finds significant joy, purpose, and meaning in her work.

Throughout the initial scenes of the movie, Alice appears confident and is depicted as someone with a great deal of self-efficacy with respect to her work. When she first experiences difficulty finding her words during a well-practiced lecture, her audience is silent. Alice breaks the silence with a joke that elicits a laugh, saying, "I knew I shouldn't have had that champagne."

A significant shift in the film occurs when Alice gets lost while running in a familiar area. This is the first scene where the emotion of fear is evident in the protagonist; there is a shift toward an external locus of control, a personal belief that Alice's situation is beyond her own control. During this scene, film effects are utilized to help the viewer experience Alice's emotions. As Alice becomes lost, the depth of field becomes extremely shallow, blurring out everything but Alice; instrumental music fades to a dull echo. The scene lasts nearly a minute until the depth of field returns.

QUESTIONING IDENTITY

After receiving a diagnosis of AD, Alice struggles to accept her new identity as someone with dementia; she uses adaptive strategies to help her overcome early levels of impairment and to mask her decline from her family. Alice's premorbid lifestyle and habits and her lack of understanding of her family history and genetic predisposition to AD, have made her appear to have a low risk for cognitive dysfunction. That reality can

make acceptance, or even consideration, of the possibility of contracting AD challenging for a family whose values are so deeply rooted in intellectual identity.

SUB-THEME: PRESERVATION OF SELF

Without telling her family, Alice initially seeks to bolster her sense of self-control through multiple analog-and technology-based methods. She quizzes herself on word-recall while cooking. In addition, she dismisses her family so she can concentrate on making a previously memorized bread pudding recipe, for which she eventually must find a recipe using the Internet search engine on her phone.

Alice also begins to visit a neurologist to discuss her increasing memory lapses—unbeknownst to her family. An initial diagnosis is difficult as she has limited family history; her mother and sister died young and she describes her father as, “Incoherent. Incontinent. Um, to tell you the truth, we didn’t see a lot of each other.” Despite her neurologist’s urging, she does not bring her husband or a close relative to their second meeting, stating: “I really didn’t think that would be necessary.”

SUB-THEME: SHIFTING IDENTITY

Despite several attempts to hide her cognitive decline from others, she eventually discusses the possibility of having AD with her husband. Although not unkind, he is dismissive of the notion—leading Alice to become angry:

JOHN- Well I think that this is ridiculous. It’s complete bullshit, you don’t have Alzheimer’s.

ALICE- God dammit! Why won’t you take me

seriously? I know what I’m feeling. And it feels like my brain is fucking dying. And everything I’ve worked for in my entire life is going. It’s all going...

Once Alice and John receive the official diagnosis in the doctor’s office, the battle of acceptance versus denial is further complicated by strong emotions of fear, anxiety of the unknown, and worry for the future—in particular, the fear of stigma associated with AD as compared to other more socially-acceptable conditions:

ALICE- I wish I had cancer.

JOHN- Don’t say that.

ALICE- 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...social...I can’t remember the word.

At this point in the film, there is a shift in Alice, whose fear moves from regarding her own circumstances to considering those of her children, who may be affected by this inheritable disorder. Each of her children responds differently to this news; Anna and Tom appear significantly frightened, sad, and in denial. Although Lydia is saddened, she presents with a more accepting tone, also intuitive to the fact that she had noticed some changes in her mother’s behavior when others had not. The realization of Alice’s inevitable decline is something that the whole family experiences, not just Alice.

COPING AND FAMILY ROLE SHIFTS

In the third part of the film, themes revolve around coping, and the changing caregiver/family dynamics.

Alice's decline becomes more rapid; film techniques are used to show her perspective. In one scene, Alice frantically searches for her phone. In the next scene, John discovers the phone in the freezer. Despite Alice's stating that she was looking for the phone "last night," John quietly tells Anna: "That was over a month ago."

SUB-THEME: COPING

Alice attempts to maintain control of her destiny by creating an elaborate plan to test herself cognitively each day, then commit suicide once she is not able to answer a set of questions she has created. Eventually, however, Alice embraces her disease—culminating in a presentation to an AD advocacy group. Alice tells the audience:

"All my life I've accumulated memories; they've become, in a way, my most precious possessions...everything I've worked so hard for. Now all that is being ripped away...I still have moments in the day of pure happiness and joy. And please do not think that I am suffering. I am not suffering. I am struggling. Struggling to be a part of things. To stay connected to who I once was."

SUB-THEME: CHANGING CAREGIVER/FAMILY DYNAMICS

As Alice's symptoms of AD progress and change, so do the roles of the family members. John shifts from husband, in equal standing with his wife, to caregiver, who has to assist Alice with activities of daily living. Although John attends to his caregiving duties, he withdraws in the area of emotional support. John displays coping behaviors by focusing on his work, and by declining Alice's multiple requests to spend more time with her despite her pleas that "this might be the last year that I'm myself."

Anna demonstrates infantilizing behavior (treating the other as a child) by discussing Alice's health with others without acknowledging that Alice is present. The viewer notices a change in their relational dynamic, although subtler than John's actions: Anna declines her mother's support after receiving the confirmation that she has the gene for AD; she stops playing a technology-based word game with Alice. Again, as with John's emotional withdrawal, infantilization is likely a coping mechanism for Anna, who is creating distance or space between herself and her mother. It is indicative of Anna's not wishing to witness what her life may possibly be like in the future, now that her own likelihood of developing AD has been established.

Lydia, who was previously estranged from her family, slowly strengthens the bond with her mother and eventually becomes her caregiver. She also makes attempts to understand more about her mother's experience. This strengthened bonding creates an acknowledgment of Alice inclusive of her AD that she is grateful to receive:

LYDIA- What is it like? I mean what does it actually feel like?...

ALICE- I've always been so defined by my intellect...I don't know what I am going to lose next.

LYDIA- It sounds horrible.

ALICE- Thanks for asking.

Lydia's empathic, rather than fearful approach, embracing the diagnosis rather than denying or shying away from it, creates a deeper connection that continues as Alice experiences greater levels of cognitive decline.

Discussion

The film *Still Alice* presents an example of how multiple intertwined relationships affect the perception of experiencing AD. A rich understanding of premorbid contexts and reactions between and within characters distinguishes *Still Alice* from other films, particularly as many others tend to isolate the character with AD, focusing on how they are different from people without the disease.^{9,14} As with the circuit of culture, this treatment of other people as different than oneself helps create and reinforce meaning, particularly among those with limited contact with persons who have AD.⁵ These representations of persons with AD in film are counterproductive for this population. Previous studies have identified the importance of social connectedness among the AD population for promoting resilience.²⁶ As such, Socio-emotional Adaptation Theory was used as a guiding framework for understanding how psychosocial resources, including social connectedness, were represented in *Still Alice*.¹⁶ Films that present a broad range of emotional reactions among persons with AD of varying abilities are important for shaping social discourse.

PREMORBID CONTEXT

In the current study, we found premorbid context to have an important role in the shifting family dynamics as Alice's disease progressed. Prior to her diagnosis, Alice is represented as a strong, career-minded person who was "relentless" and "wanted everything and all at once." After her diagnosis, however, she and her family struggled with a shifting self-perception of roles and identities. Alice and John's marriage shifts from an egalitarian relationship to one that requires increasing care provided by one partner. Previous studies have found that this change in relationship status can be

tumultuous.^{16,27} The trajectory of relationships evident in the film ranges from avoidance (Anna), to conflicted (John), to embracing (Lydia).

SENSE OF SELF

This study also identified the protagonist's strong need to preserve a sense of self despite declining physical and cognitive abilities. A preserved sense of self is achieved first through denial, followed by fear and anger, then finally acceptance, when she gives a speech to an Alzheimer's advocacy group. Indeed, as mentioned previously, participation in socially meaningful activities has been shown to increase resilience among older adults.²⁸ Yet, these emotions are not isolated, and instead shift in response to changing psychosocial circumstances such as the changing relationship expectations and balance between Alice and her family.

FILM AS TEACHING TOOL

The film *Still Alice* is potentially beneficial as a teaching tool for students who will be interacting with individuals with AD and their loved ones. Use of art and media in the classroom has been shown to be beneficial, as it engages the learner through multiple senses, including visual and auditory.²⁹ Furthermore, media- or art- based learning activities can be especially useful where certain diagnoses are difficult to imagine, or are misunderstood, as in the case of a person with AD, or individuals with mental illness.^{11,30} Studies demonstrate that implementation of media-based activities in the classroom has a significant impact on individual perceptions of older persons—a group that is often misunderstood and negatively perceived by society.³¹ Healthcare workers and society at large often hold negative perceptions of individuals with AD, such as the expectation that they are "ornery."²² These negative perceptions are held often by the same

individuals who are charged with caring for them—thus posing a barrier to optimal care. Utilization of the film *Still Alice* in the classroom may provide learners with a different perspective of those diagnosed with AD, and has the potential to shift students' and healthcare workers' perceptions of individuals with AD from a primarily negative perspective to a more positive one.

Limitations

In the current study, we present results from the analysis of one film—chosen based on critical reviews and the knowledge that the person with AD was the central character portrayed in it. Although others have reviewed themes across multiple films addressing AD,^{12,13} we chose to examine a single film using rigorous qualitative methods. There are some limitations to our findings and results.

Although the portrayal of Alice does present a nuanced account of the experience of AD, several important characteristics of hers are atypical of the general AD population. In particular, early-onset AD affects a small subset of the population. (Alice is aged 50 years at its onset.) Further, as with many other films' representations of AD, Alice is a highly-educated person with high socio-economic resources and familial support.¹³ For example, Alice eventually has a non-familial caregiver (Elena), continues to live in an expensive city (New York) despite her husband's moving to another city, and has her daughter move from across the country to live with her. The film also only highlights the relationship with a single physician, rather than the team of clinicians that affects the care of a person with AD. Further, her physician is rarely highlighted in the film. Previous studies have indicated that the relationship with various clinicians, such as physicians and nurses, can affect the patient's

emotional response to their cognitive decline.¹⁶

Conclusion

Film can be a “powerful socializing agent;” it can provide the opportunity for deeper reflection on one's own identity, and help a viewer understand elements of another person's unique lived experience.³² Gaining perspective of what it is like to live with AD has important implications for society. AD has been classified as the 12th most burdensome disease in the United States, taking into account the impact of functional disability, caregiver burden, and years of life lost.³³ A film such as *Still Alice* helps the audience appreciate the psychosocial implications that accompany a diagnosis of AD. It also delivers a strong message about the importance of resources, and family relationships, and how these factors directly affect emotions and coping. *Still Alice* depicts the lead character's initial diagnosis and early progression of the disease. The portrayal of AD in *Still Alice* is different compared to a majority of media sources that focus primarily on the latter, more severe, stages of the disease, where the person with AD is depicted with limited independence, awareness, and decision-making ability. Showing a range of decline helps the audience recognize the progressive nature of AD, as well as understand the importance of retaining self-identity and dignity in its later stages.

The themes that emerge from the analysis of *Still Alice* are significant because they demonstrate film's ability to portray the complex interplay of self-concept, emotions, family dynamics, and coping mechanisms that may be experienced by a person with AD. Gaining a deeper understanding of how a person's emotions and self-identity change with the progression of AD will help healthcare workers and caregivers respond to and care for these individuals more effectively.

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Sarah Caston, PT, DPT, NCS is an Assistant Professor in the Division of Physical Therapy, Department of Rehabilitation Medicine. She received her BS in Rehabilitation Science from the University of Pittsburgh in 2008, with a certificate in Psychosocial Issues in Rehabilitation and Self Care. Dr. Caston is an alumnus of the program and she received her Doctor of Physical Therapy degree from Emory University in 2011. Dr. Caston was a clinician for a number of years before joining the division as a faculty. She obtained her neurologic clinical specialist certification in 2013 and became an APTA Credentialed Clinical Instructor while in clinical practice. Dr. Caston's primary teaching responsibilities within the DPT program are courses related to geriatric and neurologic rehabilitation, and she serves as Assistant Director of Clinical Education.

Dr. Caston's current areas of interest and patient care include neurologic and geriatric rehabilitation, qualitative study regarding lived experiences of those living with a disability. Currently, her scholarship is active in the areas of upper extremity recovery and caregiver experience related to stroke survivors, the use of media in the classroom to depict individuals with neurologic impairments, and methods of dual task training in the neuro-geriatric population. Consistent with a holistic approach toward patient care and teaching, Dr. Caston also has a passion for the incorporation of humanities in rehabilitation, and serves as a faculty assistant editor to the *Journal for Humanities in Rehabilitation*, and a member of the Consortium for the Humanities, Ethics and Professionalism through the American Council of Academic Physical Therapy. Dr. Caston also has a passion for international service learning and has been a clinical instructor and faculty mentor for a community outreach program serving individuals with chronic stroke since 2012.