Narrating the Fragmenting Brain: Alzheimer's Disease Neuronarratives

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NARRATING THE FRAGMENTING BRAIN: ALZHEIMER’S DISEASE NEURONARRATIVES

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This dissertation examines the representation of Alzheimer’s Disease (AD) neuronarratives (NN), works that centralize the brain or consciousness in the plot, in multiple modalities to support that argument that neuronarratives should be expanded into a transmedia genre. These modalities include neurogames, neurocomics, and neuromemoirs. These three modalities were analyzed to determine how selfhood and social networks are represented by characters or authors with Alzheimer’s Disease. As AD is often viewed as the loss of selfhood and is associated with isolation, these works combat these stigmas and complicate representations of the disease. The use of images was also examined in neurogames and neurocomics as a means of expressing complex emotions without relying on text. As the selected neurocomics were written by carers or based on experiences with AD patients and the neuromemoirs were written by AD patients, these works were also analyzed as a means to provide agency for AD patients and carers.

This dissertation approaches these neuronarratives through the lens and medium of hypertext. Applying this approach complicates the concept of fragmentation and memory in AD NN and reveals that selfhood in these works are constructed through the creation of many selves rather than one cohesive self or a dual self that represents the healthy and ill AD patient. Regardless of the medium, these selves remain in conversation with each other, emphasizing the active process of creating selfhood by the author’s themselves and by the player or reader. Comparing the affordances and limitations of the medium reveal conversations between the digital and print mediums that may not be initially apparent. Viewing these works through hypertext de-centers AD at the core of the narrative and instead emphasizes the personhood of...
the patient. Expanding analytical approaches to transmedia NN provides new means of exploring selfhood and consciousness by writers, artists, and developers.
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# TABLE OF CONTENTS

ABSTRACT .................................................................................................................. iii

INTRODUCTION ........................................................................................................... 1

Alzheimer's Disease ........................................................................................................ 2

Alzheimer's Disease Neuronarratives ......................................................................... 3

Research Questions ....................................................................................................... 6

Review Of Materials .................................................................................................... 9

Neuronarratives .......................................................................................................... 9

Neurogames ............................................................................................................... 10

Neurocomics .............................................................................................................. 14

Defining Neuromemoir .............................................................................................. 17

Core Characteristics Of Neuromemoirs .................................................................... 20

Hypertext As A Lens and Medium ............................................................................ 22

Methodology And Project Design ............................................................................. 26

Selfhood ...................................................................................................................... 27

Social Connections .................................................................................................... 28

Affordances and Limitations of the Medium ............................................................. 29
Environment ................................................................. 31

Agency.............................................................................. 32

Chapter Summaries .......................................................... 33

CHAPTER 1: I SPY A MEMORY: NEUROGAMES AND ALZHEIMER’S DISEASE .... 36

Introduction ...................................................................... 36

Games And Narrativity ...................................................... 39

Hypertext And Games ....................................................... 42

Forget Me Knot Summary .................................................. 45

Selfhood in Forget me Knot .............................................. 46

Social Connections In Forget Me Knot ............................... 50

Environment In Forget Me Knot .......................................... 53

Alzheimer’s Memories Summary ......................................... 55

Selfhood In Alzheimer’s Memories ...................................... 56

Social Connections In Alzheimer’s Memories ....................... 59

Environment In Alzheimer’s Memories ............................... 63

Before I Forget Summary .................................................. 67

Selfhood In Before I Forget .............................................. 68

Social Connections In Before I Forget ............................... 72
Environment In Before I Forget .................................................................................. 77

Conclusion .................................................................................................................. 80

CHAPTER 2: DRAW MY LIFE: ALZHEIMER DISEASE NEUROCOMICS ......................... 84

Introduction .................................................................................................................. 84

Neurocomics .................................................................................................................. 85

Wrinkles Summary ....................................................................................................... 89

Selfhood In Wrinkles ................................................................................................... 90

Social Aspects Of Selfhood In Wrinkles ..................................................................... 94

Environment In Wrinkles ............................................................................................ 99

Tangles Summary ......................................................................................................... 105

Selfhood In Tangles ..................................................................................................... 106

Social Interactions In Tangles ..................................................................................... 109

Environment In Tangles .............................................................................................. 116

Aliceheimer’s Summary ............................................................................................... 120

Selfhood In Aliceheimer’s .......................................................................................... 122

Social Relationships In Aliceheimer’s ......................................................................... 125

Environment In Aliceheimer’s ..................................................................................... 127

Conclusion ..................................................................................................................... 129

viii
CHAPTER 3: FORGET ME NOT: NEUROMEMOIRS OF ALZHEIMER’S DISEASE

Introduction .................................................................................................................. 133

Neuromemoirs ............................................................................................................. 135

Tattoo On My Brain Summary ..................................................................................... 138

Selfhood In A Tattoo On My Brain ............................................................................ 139

Social Connections In A Tattoo On My Brain ............................................................ 143

Agency In A Tattoo On My Brain ................................................................................ 145

Memory’s Last Breath Summary .................................................................................. 148

Selfhood In Memory’s Last Breath ............................................................................. 149

Social Connections In Memory’s Last Breath .............................................................. 152

Agency In Memory’s Last Breath ................................................................................ 155

Somebody I Used To Know Summary ........................................................................ 157

Selfhood In Somebody I Used To Know .................................................................... 158

Social Connections In Somebody I Used To Know ..................................................... 163

Agency In Somebody I Used To Know ....................................................................... 165

Conclusion ................................................................................................................... 168

CONCLUSION ................................................................................................................. 171

Research Question 1 ................................................................................................... 172
Research Question 2.............................................................................................................. 175
Research Question 3............................................................................................................. 178
Implications Of The Project ............................................................................................... 181
Limitations.......................................................................................................................... 188
Areas For Future Research ............................................................................................... 189
REFERENCES ....................................................................................................................... 193
INTRODUCTION

There has been a rising interest in narrative medicine for the general public, students, and the medical and scientific communities as a means to focus on scientific research while still connecting to audiences. In *Narrative Medicine: Honoring the Stories of Illness*, Rita Charon argues that narrative medicine uses stories to increase empathy for the patients and also allows medical practitioners an opportunity to reflect on their position and practices (4). Through the process of scientific research, the stories of the people behind the data are often lost and the reality of living with a neurological condition or disease is difficult to express in scientific papers. British neurologist Oliver Sacks argued in *The Man Who Mistook His Wife for a Hat* that “to restore the human subject at the centre [of scientific papers] — the suffering, afflicted fighting, human subject—we must deepen the case history to a narrative or a tale; only then do we have a ‘who’ as well as a ‘what,’ a real person…” (viii). Rather than limiting the personhood of the patient to only their condition, narrative medicine shifts the focus back to the patient themselves and their lives in relationship to the illness. As Melanie Yergeau argues in *Authoring Autism*, narratives that center the condition rather than the person themselves create ableist narratives that lose the personhood of the individual they are trying to describe (5). Medical narratives must centralize the person themselves rather than the condition. This shift in attention to the patient also impacts medical practices. Liao and Wang found that by using narrative medicine as an interdisciplinary practice in the training of students in the medical fields increased the students’ ability to empathize and communicate with their patients (14).

The practice of implementing narrative medicine is increasing in the medical field and a genre of literature called neuronarratives, narratives that focus on a neurological condition or
disease, are another way for the public to learn more about the brain and mental health and gain more empathy for people who are struggling with a mental health condition or disease. These works also provide a means of self-expression and agency for the patients. Neuronarratives are not just limited to those in the sciences, but are another way to connect to the general public, patients, family members, or care givers. Jason Tougaw argues in *The Elusive Brain* that “literary representations of “all manner of neurologies” help make what’s hard to see visible and invite engagement with difference. They emphasize the difficulties and disjunctions as well as the benefits and opportunities for personal and cultural transformation involved” (233). This dissertation argues that neuronarratives must be expanded to be considered a transmedia genre of works. Neuronarratives come in a variety of forms and mediums all of which can provide engagement and understanding about a wide range of conditions from those interacting with the materials.

**Alzheimer's Disease**

For the scope of this dissertation, I will be focusing on neuronarratives on Alzheimer’s Disease (AD). Though the direct cause of AD is still unknown, it is a neurodegenerative disorder that is marked by an increase of by β – amyloid plaques and tau neurofibrillary tangles (Knopman *et al*.). The symptoms of AD vary slightly by person, but all AD patients experience memory loss which eventually leads to loss of cognitive function. Knopman *et al.* also note that in patients over 65, it is common for AD have co-morbidity, or have diagnosis of other conditions alongside AD. Though there are increased risks of developing AD if family members have been diagnosed with the disease, genetics seem to only have a modest impact on the
likelihood of diagnosis (Knopman et al.). While previously only diagnosable after the death of the patient or when diagnostic tests had ruled out other diagnoses, AD is now diagnosable through cerebral spinal fluid (CSF) tests and PET scans (Knopman et al.). A diagnosis of AD is given to those who are 65 years or older and patients diagnosed with AD before they are 65 are given the diagnosis of early-onset AD. There are no known cures for AD and the current research is focused primarily in delaying or alleviating the symptoms and providing care and comfort to patients as they move through the stages of AD.

This is a timely topic given the growing number of Alzheimer’s patients. The Mayo Clinic’s “Alzheimer’s Disease” page states that in the United States alone, 5.8 million people who are at least 65 years old have Alzheimer’s Disease. Worldwide, around 50 million people have dementia and 60-70% of these cases are Alzheimer’s Disease (“Alzheimer’s Disease”). As the US “Baby Boomer” population continues to age, this disease is likely to continue to increase, raising more concerns regarding the health and treatment of the aging population, especially given that specific generation’s size compared to following generations. As the on-going COVID-19 pandemic has shown, there is a critical need to relay scientific and medical information to the public, so boundary work research on medical narratives such as neuronarratives in a variety of modalities has larger implications about the value of narratives as a method to connect audiences with a disease or condition.

**Alzheimer's Disease Neuronarratives**

There has been some research into how memory conditions impact the concept of self in neuronarratives. My previous work “The Fractured Self” published in *EJAS*, focused on how
Capras Syndrome and anti-NMDA receptor encephalitis impacted the main character’s ability to identify themselves in the neuronovel *Echo Maker* and *Brain on Fire*. In the same volume, Jason Tougaw discussed memory and identity in works with amnesic characters, noting that identity is not limited to the self, but is also seen in the relationships to others and the overall environment of the characters. He argues that “these literary texts remind us how important the dynamic between remembering and forgetting will be to future research,” as they complicate the concept of identity and selfhood (Tougaw). Characters in these works must re-create their sense of identity or rely on others to fill in blanks. While amnestic stories are often viewed with some disdain as soap opera troupes, these narratives do reveal the complicated nature between our sense of self and how that impacts our relationships to others.

There have also been several papers on Alzheimer’s Disease narratives. Authors such as Więckowska notes that these works shift the focus of self from the main character to an intricate construction of perceptions from their loved ones in tangent with their own. She argues that AD narratives are unique as a genre, “through its semi-documentary character and the intention, sometimes explicitly expressed, to shape the public perception of the illness and those suffering from it” (68). While some of these works are specifically designed as self-help books or are a collection of materials intended to provide coping strategies for family members, others focus on battling stigmas or preconceived ideas of AD (Więckowska 68-69). Więckowska notes that a common theme in AD narratives are feelings of isolation from the AD patient, either from the community as a whole, their friends, or their family members who are unable to cope with their illness. Więckowska notes that AD works show the need for community in “… the relation
between memory and identity, where the responsibility to preserve the forgetting self and its memories is relocated onto others,” thus making the self a network rather than an individual (73).

Krüger-Fürhoff makes a similar argument, though she focuses on the ethical benefits and agency that AD narratives provide to patients and their families. She argues that neuronarratives “challenge the Western concept of an autonomous subject that can tell his or her own life story” and these narratives raise ethical concerns as the present “first-person-based or imaginary insights into the experience of people with dementia, which no other discourse (e.g., that of the medical community or of caregivers can provide” (91). Krüger-Fürhoff’s article does have some limitations as it focuses on male authors with AD and on the comparison “between [their] narrative selves and their pending post-narrative conditions” (93). While Krüger-Fürhoff points out that neuronarratives have the benefit of providing a sense of agency to these patients, she argues that these neuronovels do not help readers understand what it is like to have AD, so expanding on her research with different modalities would be beneficial to show how AD representations vary based on modality.

Though there has been scholarly work on Alzheimer’s Disease narratives, comparing how Alzheimer’s Disease narratives are impacted by modality remains largely ignored. Vargas et al. does address two novels Vizzini’s It’s Kind of a Funny Story, Ness’s The Rest of Us Just Live Here, and in the Ninja Theory’s video game Hellblade: Senua's Sacrifice; however, their focus remained on how these works were examples of positive portrayals of mental illness. They also focused on three separate conditions (clinical depression, OCD, and schizophrenia) which makes comparing these representations to each other more difficult. Vargas et al. does call for more research into video games as means to portray and explore mental health, and I hope to fill this
gap through this dissertation research to address how the affordances and limitations of the modality of the works and how these modalities impact the AD neuronarratives and representations of AD patients.

**Research Questions**

Humans are natural storytellers, and these stories are not just for our entertainment, but are part of our very identity. Sacks argues that we create ourselves through “… narrative, which is constructed, continually, unconsciously, by, through, and in us— through our perceptions, our feelings, our thoughts, our actions; and, not least, our discourse, our spoken narratives” (110-111). I would push this further to argue that it is not just our spoken narratives, but our written, drawn, and coded narratives that help us express ourselves. Though many may be familiar with other forms of media discussing AD such as movies like *Still Alice* (2014), documentaries like *Complaints From a Dutiful Daughter* (1994), or even well-known printed works such as Greg O’Brien’s *On Pluto* (2014), there are many neuronarratives that express the experiences of AD that have not been discussed in depth nor is there much discussion of the comparison of different mediums and their impact on AD neuronarratives. Jenell Johnson utilizes this approach of the narrative in her text *American Lobotomy*, as she argues that narratives regarding science go beyond medical reports and scientific papers and are also present in asylums, video games, comics, and haunted tours. For my dissertation, I argue that a similar approach to Johnson’s research may be taken with neuronarratives that focus on Alzheimer’s Disease.

I approach these Alzheimer’s Disease neuronarratives through the lens and medium of hypertext to view the different mediums including: text, images and text, and digital works,
through a multilinear structure and see the mixture of media and perspective as another level of content rather than intrusive or interruptive. Applying hypertext to these works is appropriate as David Bolter argues hypertext not only connects different forms of media together, but it can be used as a lens to view a work. I review three different types of neuronarratives: neurogames (NG), neurocomics (NC), and neuromemoirs (NM). Through these works, we strive to create an understanding of what it is like to experience our lives—our experience of consciousness. In his famous article “What is it like to be a Bat?” Nagel postulated that we can only ever imagine ourselves as something else; even in bat form, we can only be ourselves as a bat because it is so difficult to create a full understanding of reality from someone else’s perspective. When illness compromises a person’s sense of consciousness, understanding their experiences becomes even more difficult. NG, NC, and NM attempt to help audiences enter into the mindset of someone else to gain a greater understanding of their experiences.

Viewing neuronarratives of Alzheimer’s Disease (AD) through the lens and medium of hypertext allows the fragmentary nature of the illness to be expressed alongside the main narrative and scientific information. Reading these AD neuronarratives this way complicates perceptions of selfhood as a linear process and instead presents how the brain, environment, and social groups come together to create a sense of self. Through the lens and medium of hypertext, I examine how the modality of the narrative impacts neuronarratives on AD as well. This dissertation will discuss three neuronarratives in each of the following modalities: digital games, printed comic, and printed text. While research has been done on individual works, there is very limited research on the affordances and limitations of the modality of these narratives. My overarching research questions are:
1. *How do the representations of Alzheimer’s Disease patients in neuronarratives complicate our understanding of the concepts of identity and memory?*

2. *How does reading neuronarratives through the lens and medium of hypertext complicate the idea of fragmentation of memory and selfhood in these narratives?*

3. *How does the modality of the neuronarratives complicate or impact the representation of Alzheimer’s Disease?*

While Alzheimer’s Disease is often viewed as a slow disintegration of self, NG, NC, and NM emphasize the humanity and selfhood of Alzheimer’s patients and their families. Sacks argues that “to be ourselves we must have ourselves — possess, if need be re-posses, our life-stories. We must ‘recollect’ ourselves, recollect the inner drama, the narrative, of ourselves. A man Needs such a narrative, a continuous inner narrative, to maintain his identify, his self” (111). NG, NC, and NM explore not only the patient’s loss of memory and functions, but also provides insight into the impact on those around them; both mourning and celebrating their memories as they reach the end of their lives. As all of the characters or authors discussed within this dissertation were diagnosed with AD, when I refer to multiple works at once, I will refer to the characters or authors as AD patients. This term is not intended to lessen the personhood of the individuals within these works, but rather as a description for a group. This dissertation focuses on how these works in different modalities utilize text, images, and interactivity in both print and
digital formats to represent Alzheimer’s Disease to their audiences. NG, NC, and NM that focus on representations of Alzheimer’s Disease complicate the idea of self and memory as their narratives seeks to show the fracturing memories while also empathizing the personhood of the patient.

**Review Of Materials**

**Neuronarratives**

The term neuronovel came from Marco Roth in a scathing article critiquing these works that tried to pull in scientific terminology or background as a core part of their narratives. Roth believed that a reliance on science was a symptom of weak writing. Gary Johnson argues against Roth in his article “Consciousness as Content,” claiming that “as scientists learn more about the general human phenomenon of consciousness, novelists find themselves forced to rethink how that phenomenon manifests itself in their individual narratives” and that is what neuronovels attempt to do (Johnson 172). Neuronovels do share some similarities with streams of consciousness as some of these works may write in that style to provide insights into the characters thoughts; however, neuronovels “at their most basic level… aspire to mimesis, the realistic depiction of an individual's consciousness” (Johnson 170). While thoughts are certainly part of the conscious experience, Johnson argues that neuronovels go beyond streams of consciousness to debate where consciousness itself comes from. Instead of neuronovels, Johnson described “neuronarrative” as “a work of fiction that has cognitive science as a, or the, main theme” (170). This term is now used as broader category, including both works of fiction and memoirs (also referred to as neuromemoirs or brain memoirs). Some common neuronarratives
include Kay Redfield Jamison’s *An Unquiet Mind: A Memoir of Moods and Madness*, Richard Powers’ *The Echo Maker*, Mark Hadden’s *The Incident with the Dog in the Nighttime*, John Wray’s *Lowboy*, and Ian McEwan’s *Saturday*. These works vary in how they express their narratives, but at their core, they focus on some neurological condition or disease. For Johnson, neuronarratives are “…an emerging subgenre of literature that can provide us with a glimpse of how authors are responding to scientific advances concerning the nature of human consciousness” (Johnson 170). I will be using the term neuronarratives to refer to works including neuronovels, neurogames, neurocomics, and neuromemoirs.

**Neurogames**

The first of the modalities this dissertation will discuss are neurogames (NG). I am defining neurogames broadly as a narrative driven game that focuses on a neurological condition. While this term has not been used in scholarly research, using digital media to explore consciousness is not a new field of study. Marie- Laure Ryan argues in *Avatars of Story* that “new media” is an attempt to use new technology to create or better understand identity or sense of selfhood (xi). Ryan argues that the medium of the narrative is critical as it provides unique affordances and limitations on the way the narrative is expressed (Ryan 27). Astrid Ensslin builds on Ryan’s work in *Literary Gaming* as she argues that the interaction between gaming and reading impacts the experience of the work (6). Ensslin emphasizes that there is no one way of reading digital works which adds to the flexibility of digital works in terms of user experiences (6). As these games offer representations of the same disease, noting how AD is represented within their narratives will provide a useful point of comparison.
Scientists such as Fordham and Ball argue that the development of these games can result in a more realistic expression of mental illness and can be beneficial in promoting empathy and addressing stigmas regarding mental health conditions (10). The focus of their research was the game *Hellblade: Senua’s Sacrifice*, which focused on psychosis. They also noted that the game was effective due to the collaboration with the scientific community to present the condition in a respectful manner and incorporating information about the condition in the gameplay (Fordham and Ball 10). While some critics argued that this combination of information and gameplay was as a trivialization of the condition, the authors argued that this combination makes the condition more approachable and the incorporation of the storyline and condition smoothly addressed inaccuracies in the stigmas surrounding mental health (Fordham and Ball 11). The critiques of how the condition is incorporated into the gameplay without either trivializing or stigmatizing the condition remains a common concern. While this issue of educating and being respectful while also incorporating this information into a game remains something that developers must continue to address, Fordham and Ball note that incorporating games into the coursework of students in the medical field is becoming more common.

R Lyle Skains argues that digital narratives offer several opportunities for both the writer and reader. While there are concerns regarding the structure of hypertext making the narrative more convoluted through the navigation of different links and more time consuming to investigate all aspects of a work, Skains’ research suggests that this “fragmenting” process can allow the reader to experience “alternate perspectives, approaches, structures, and expression” that they would not experience in traditional forms of literature (189). Users are now more accustomed to multimedia narratives, seen in increased interaction with different forms of media,
so while previous authors have argued that using a collection of different types of digital media together could result in unreliable narrators, Skains argues that these words can still be read as a collaborative whole. By utilizing digital media, stories such as neuronarratives can pull from multiple modalities to allow the reader to connect more clearly to the author and gain a unique understanding of the condition.

Materials : Neurogames

With this in mind, I chose three neurogames that focus on AD:

1. Alexander Tarvet’s Forget Me Knot (2020)
2. Gillian Yue’s Alzheimer’s: Memories (2021)
3. 3-Fold Games’ Before I Forget (2020)

*Forget Me Knot* is the shortest of the three games, lasting about twenty minutes, but it received a positive reception. Matt Brian from Engadget praised the game and notes that games like *Forget Me Knot* “understand different perspectives on life” and these games are “somewhat under-utilized,” but games like Dys4ia and Depression Quest, show the players’ interest in these types of games. Mark Steighner on Hardcoregamer notes that games about AD are particularly interesting as research has been mixed on games either increasing the likelihood of AD through the loss of gray matter or hindering the progression of AD through mental simulation and puzzle solving. However, games like *Forget Me Knot* provide a means for players to explore AD in a short, but detailed narrative and may lead them to research more on the topic after playing.
Alzheimer’s Memories is rated positively on Steam with 36 positive reviews and only 1 negative review. As several of these reviews were not in English, Google Translate was used to read them. Many reviewers appreciated both the art and emotional nature of the story. Rachael Brearton from the Indie-hive notes that Alzheimer’s Memoires shows the nature of AD without being “bleak” through the inclusion of the memories and interactive elements. She does critique the lack of a save option, which requires the player to play through the entire game in one sitting and does not allow check points, but argues that it is “touching experience with clever styling choices that really tie in the narrative.” Several reviews on Steam also emphasize both the benefit of the first person perspective for empathy and educational value for people with an interest or loved one with a diagnosis of AD.

Before I Forget was a BAFTA award nominee and has a high positivity rating on Steam with 92 positive reviews, and of 71 those reviews were rated highly positive, and only 7 negative reviews. The positive reviews focused on the emotional connection they had with the story and several reviewers connected the game to experiences they had with their family members who struggled with AD or dementia. They also praised the artwork and style of the game. The negative reviews commonly complained of a predictable plot line and depressing story with a few complaints about the game mechanics. Nicole Carpenter from Polygon argues that while this game is sad and can feel frightening, the basis of this lies in the reality of the disease rather than using it as a narrative plot device. While the loss of Sunita’s memories is tragic, through the emphasis of Sunita’s life, the game showcases that dementia does not over encompass her identity.
Neurocomics

The second modality in this dissertation are neurocomics. In my previous work “Restless Figures,” an article on digital horror comics published in *ImageText*, I created my definition of comics through the combination of Scott McCloud’s and Jen Aggleton’s definition of comics. Scott McCloud argues in *Understanding Comics* that comics are “juxtaposed pictorial and other images in deliberate sequence intended to convey information and/or to produce an aesthetic response in the viewer” (21). Jen Aggleton created her definition in her work with the British Library’s digital cataloging project that combined visual, interactive, and cultural aspects of the comic and included a digital version of a print comic if the digital version added unique elements (Aggleton 397). For the scope of this dissertation, I am defining comics as works that combine images and text in either print or digital form to create a narrative. This definition is still very general, so I also narrowed further by reviewing the genre of science comics and graphic medicine.

Two common terms for comics that focus on scientific or medical conditions are Science Comics and Graphic Medicine. Science comics are defined as “the genre of comics for which science education is a primary goal” (Jee and Anggoro 197). Using this definition, science comics are limited to specifically educational works, so works that utilize narrative as the main purpose rather than education would not fit within this category. In *Graphic Medicine Manifesto*, Czerwiec et al. defines the term graphic medicine as, “the intersection of the medium of comics and the discourse of healthcare” and claims that “graphic medicine combines the principles of narrative medicine with an exploration of the visual systems of comic art…” (Czerwiec et al. 1). This term is more general compared to science comics as works under this category do focus
on narrative, but the phrase “discourse of healthcare” varies widely within this series. For example, within this series of publications are works on women’s rights and access to abortion, struggles with fertility, Parkinson’s Disease, discussions of disabilities, ethics among doctors, nurses, and other healthcare workers, and Alzheimer’s Disease. As this term can refer to such a wide range of topics and audiences, I chose to use the term neurocomic to refer to works specifically about the brain or brain conditions. This term comes from the work *Neurocomic* by Matteo Farinella and Hana Roš. Admittedly, the use of this term is limited as many other scholars switch between neurocomics and science comics or graphic brain narratives. However, as the term neurocomic is very specific to comics that center brain disease or brain conditions as their narrative, and as that is the topic of this dissertation, I will use the term neurocomics for this category. Neurocomics combine media, allowing the expression of external and internal concepts that are difficult to set up with text alone.

Materials: Neurocomics

With this in mind, I chose three AD neurocomics:

1. Paco Roca’s *Wrinkles* (2007 translated to English 2016)
3. Dana Walkrath’s *Aliceheimer’s: Alzheimer’s Through the Looking Glass* (2016)

These works all include a combination of images and text for the narrator to tell their experiences with AD patients. While Roca’s work is technically fictional, he based the work on his experience with AD patients. While Roca’s work is older, I argue that his unique perspective
of portraying AD patients, the fact that his was one of the first portrayals of AD in a graphic
format, and the relative newness of the English translation of his work merits his inclusion in this
dissertation. Both Levitt and Walrath describe their experience with their mothers’ AD. Levitt’s
work is the densest of the work that shows the author’s experiences with her mother from before
her diagnoses to mourning her death. Walrath’s work has been shown in different modalities
including an art exhibit and an opera, but for the scope of this dissertation, I will focus on her
printed work. Her work is unique in the utilization of Alice and Wonderland to cope with her
mother’s condition. These comics are unique in their ability to utilize images and text to
showcase the subjective experiences of AD patients’ carers while also expressing the author’s
understanding of the disease and diagnosis. These neurocomics show text and images as a crucial
method of expression.

Laura Sneddon from Publisher’s Weekly Online praises Wrinkles for not being afraid to
address the fear and sadness associated with AD, but praises the work for also showing how
despite the reality and inevitability of the ending, how friendship and fellowship restores the
humanity of these patients. Julius Percell from The Guardian emphasizes the benefit of the
medium to allow for different types of narratives in Wrinkles noting the “Abrupt cuts from his
characters’ befuddled present to their deep past function both as narrative and empathetic device,
conveying the sickening ellipses of memory, the seepage of vocabulary, the bewilderment” all
convey their experiences with AD and mix present with past. Kirkus Reviews notes that Tangles
shows the wide impact of AD on not just Leavitt’s mother, but the entire family. They note that
while AD is featured prominently, the emphasis remains on the individuals of the family. James
Smart from The Guardian notes that while the art style itself is simple, Tangles is able to clearly
express the complex emotions of the family as they adjust to the changes created by Midge’s AD. Finally, Daniel Smith from the University of Georgia argues that *Aliceheimer’s* medium allows for more accessibility in readers and acknowledges that he may not have read it, except for the fact that it was in a graphic medium (3). Smith argues that “*Aliceheimer’s* provides a way to introduce and education people about a medical condition while highlighting the humanity involved in dealing with it as a family” (4). Reviews for these works as whole note the emphasis on the humanity within AD and the development or change in social relationships as the AD patient continues to worsen. While there may be cultural references or differences in these works that may not be apparent to a reader outside of those cultures, AD neurocomics reveal the universal struggles with AD and how family members and carers (also known as caregivers) cope with and overcome these difficulties.

**Defining Neuromemoirs**

The final modality within this dissertation are neuromemoirs. In *The Elusive Brain*, Jason Tougaw reviews a series of brain memoirs, here referred to as neuromemoirs, a term that is often used interchangeably with brain memoir, and argues that these memoirs are “chronicles of the push-pull between their selves and their brains” (74). These works are a representation of the writer’s experiences but also an example of how they are responding to their altered brains (Tougaw 74). Some examples of neuromemoirs include: *An Unquiet Mind: A Memoir of Moods and Madness* by Kay Redfield Jamison, *Thinking in Pictures: My Life with Autism* by Temple Grandin, or *Brain On Fire: My Month of Madness* by Susannah Cahalan. While the genre of memoir is well established and illness can be a primary focus of a memoir, there are distinct
differences between memoir and neuromemoir. As Tougaw points out, “brain memoirs do not let their writers—or readers—forget that they are organisms whose lives are shaped to a large degree by accidents of physiology, culture, family, and circumstance” (Tougaw 75). Though Julian Henneberg argues in his book Subjects of Substance that NM should be viewed in relationship to other memoir frameworks, he acknowledges the unique qualities of NM to integrate the body and mind, restore a sense of agency to the author, and to complicate the duality of mind and body (114-117). Another critical characteristic of NM is the “elasticity” of the genre to include scientific research alongside personal narrative and reflection of the concept of selfhood (Henneberg 116-117).

Materials: Neuromemoirs

With this in mind, I chose three autobiographical works from a person with AD:

2. Gerda Saunders’ Memory’s Last Breath (2017)
3. Wendy Mitchell’s Somebody I Used to Know (2018)

Gibbs’ memoir focuses on his experiences and understanding of AD with his unique perspective as a neurologist diagnosed with AD. He included images, including his own brain scans, and neurological journal references. Saunders’ work combines the narrative with specific excerpts from her journal and pictures of her family combined with images of brains as she works through her condition, showing the complicated nature of AD and how it impacts more than the patient themselves. Mitchell remains a well-known author on AD and writes a blog on
her daily experiences. Her work was chosen for her ability to weave in the narrative, past experiences, memory lapses, and first and second perspective within the same work. While I considered her brand new publication *What I Wish People Knew About Dementia* (2022), as that work is more of a self-help book for patients and carers, I chose her first publication instead to review her initial reactions to her diagnosis and how AD impacted her daily life. All of these works include some form of mixed media through images, outside references, or additional perspectives which all lend themselves to a hypertext reading, while still maintaining text as the primary form of communication.

All three of these selected neuromemoirs have been received positively. The *Dementia Network* states that *Tattoo On My Brain*, is not only “…a fascinating read but it offers great advice and reassurance to anyone who has concerns over their memory and would like to take positive steps in order to help.” While Gibbs’ work is clearly a neuromemoir, there are several sections that focus on preventative measures for those with AD or with a risk to AD including links to the MIND diet and several resources that the reader could find for themselves to better understand their condition. *Kirkus Reviews* claims *Memory’s Last Breath* is “A courageous, richly textured, and unsparing memoir” and that “Saunders crafts an eloquent, often lyrical book that, in its fragmentation, becomes increasingly affecting over the course of the narrative.” Though Woodward acknowledges the occasionally difficulty in following the branching narratives, especially without an index, he also addresses the benefit of Saunders using this writing as an exercise in memory as well as for the narrative itself. Tavris from the *Times Literary Supplement* argues that the real strength of *Somebody I Used to Know* is in Mitchell’s demand to change the language of AD patients from “suffering” to “living with” AD (27).
Edemariam from the *Guardian* writes that Mitchell “demystifies” living with AD and serves as a harsh reminder of the failures of the medical system and how Mitchell still finds ways to live her life independently, despite the disease. These reviews show the power of these neuromemoirs to share the author’s experience of AD and how this experience can impact others, whether or not they have the condition themselves.

**Core Characteristics of Neuromemoirs**

As these works do not self-define as NM, I apply Tougaw’s definition through five major categories, and while the works in this chapter do not call themselves neuromemoirs, they clearly meet the requirements for each category. First, neuromemoirs provide agency to the author (Tougaw 75). Many writers who struggle with illnesses may feel overwhelmed or defined solely by their condition and writing their memoirs provides a means of action to them. Mallory makes a similar argument about resuming "credibility" in her work regarding recuperative ethos (116). Gibbs argues that understanding the condition is one way to combat the feelings of helplessness many patients feel and that this book was his way of addressing his own diagnosis (Gibbs 7). This urge to research is echoed in Saunders’ and Mitchell’s works as well with the common argument that more knowledge of the condition would help combat the fear associated with it.

Tougaw’s second criteria is that neuromemoirs offer a means of connections to others (Tougaw 75). Though often including scientific research and medical terminology, the audience of these works is not limited to the medical community, but is wide ranging. All three authors discussed in this chapter indicate that they hope that their writing may help those who have the same or similar conditions to feel less alone and isolated. These works may also help loved ones or caretakers of someone with the same condition. For Saunders, she specifically addresses the
reader: “My book is for you: whether you or someone you love has dementia, or you’re a medical professional, or a person searching for your own self after a huge life change, or someone just plain curious, who— like me— feels that the more you know, the better you’re able to love” (Saunders xi). Saunders’ inclusion of just the curious reader who wants to understand without a particular connection to the disease supports the idea that these neuromemoir are intended for a wide audience, not just those linked to the disease being discussed.

The third criteria for neuromemoirs is that, though they may not be written with the goal of scientific research, they provide specific and detailed accounts to living with a brain disease or condition which may be helpful for the scientific community (Tougaw 75). Both Gibbs and Saunders often refer to their books as a case study of one and try to write in a somewhat scientific manner about their experiences. However, Saunders found this approach impersonal stating, “objectivity be damned. I felt completed to tell my story from the inside” (Saunders ix-x). Both Gibbs and Saunders write in a scientific style and make observations of themselves with scientists as their imagined audiences, but what makes this style of writing unique is the presence of the personal narrative alongside the research and “case study” style of writing. For Mitchell, she found that mixing her personal experiences alongside research was one of the most effective ways of speaking to others about AD. She notes that her fears and stigmas about AD were notably alleviated when watching YouTube videos of Keith Oliver, a man who was also diagnosed with early onset AD, and hearing his actual experiences with the illness to combat her preconceived ideas about her future (Mitchell 41-42).
The fourth stipulation of brain memoirs is that they “renew and invigorate philosophical debates about mind and body, qualia, memory, and relationships between self and narratives” (Tougaw 75). As all three of the authors discussed in this chapter have begun losing not only short-term memory, but also foundational memories from their lives. This will inevitably lead to a discussion about defining selfhood and who they will be in the final stages of the disease. Selfhood in neuromemoirs is discussed in length in Chapter 3.

Finally, Tougaw claims that brain memoirs provide new means of narrative structure to describe the relationship between the brain and the mind or the complicated relationship between physiological processes and consciousness that remains heavily debated (75). These memories all contain layers of narratives varying from jumps in time, different forms of media from images, brain scans, letters, or emails, and occasionally other voices from the author’s voice speaking to themselves or another person’s writing or perspective. As Gary Johnson argued that neuronovels were aimed at creating mimesis, I argue the same can be argued for neuromemoirs. These works attempt to express what living with AD is like and how the author has come to understand it through these combinations of media and narrative.

Hypertext As A Lens and Medium

Hypertext is a broad and well-researched topic, so for the scope of this paper, I will provide a brief overview of the arguments that are particularly relevant to my approach to these neuronarratives. The term hypertext was first coined by Theodor H. Nelson in 1965. Nelson viewed hypertext as “non-sequential writing—text that branches and allows choices to the reader, best read at an interactive screen. As popularly conceived, this is a series of text chunks
connected by links which offer the reader different pathways.” While hypertext take on a variety of forms, they are traditionally interactive, multimedia works that emphasize branching pathways and highlight the readers’ impact on the work. Pre-dating Nelson, Vannevar Bush proposed an early version of hypertext in his article “As We May Think.” This system, which Bush called a Memex, would provide a collection of information that connect similar topics through a series of links. Bush argued that people using this system could add their own information and experiences to the data to combine knowledge. Though some hypertexts are collections of information, others utilize this branching form to create complex narratives.

For George Landow in *Hypertext 3.0*, he argues that hypertext represents a poststructural approach to narrative, arguing that hypertext supports “Barthes’s “ideal text” or when the reader becomes the “producer” rather than the “consumer” of the text” (4). In his famous article “The Death of the Author,” Barthes argued that the reader had long been ignored in classical literary theory which is problematic as the reader is the one that makes meaning from the work. Barthes argued that critical theory must focus on the reader’s experiences rather than the author’s background or intention. In hypertext, Barthes’ emphasis on the reader can be applied as the reader must interact with the material to move forward in a hypertext and, due to the many pathways and reader inputs into the narrative, there are often many ending to a hypertextual work. For larger hypertexts that focus on multiple pathways and reader decisions, Landow argues that the boundary between author and reader begins to blur as the reader becomes a producer of the work as their decisions create the narrative. However, in his famous work *Cybertext*, Espen Aarseth disagrees with this argument. While Aarseth acknowledges that there is more reader interaction within a hypertext as readers must make choices to progress, those
choices are ultimately limited by the author of the hypertext and the structures, while often multi-linear, are also created by the author (89). While there is disagreement among scholars about the level of participation and narrative creation in a hypertext, both Landow and Aarseth agree that hypertexts, to varying degrees, blur boundaries between the layers of narrative within the works. As hypertext creates multi-linear pathways into the narrative, the narratives and characters lose a hierarchy of main and subordinate plots (Landow 45). This blurring of boundaries emphasizes the network of connections within the narrative.

These blurred boundaries and emphasis on network has lead several authors to link hypertext to human thought. In his discussion of his memex, Bush argued that the brain also “operates by association…in accordance with some intricate web of trails carried by the cells of the brain” (6). Given the similarities between his memex and his discussion of human thought, Bush postulated that a system like the memex may be able to represent the process of human thought (Bush 8). Other scholars of hypertext such as David Bolter in his work Writing Space, have made similar arguments. Bolter supports Bush’s argument that a networked system may help express the linear process of human thought and that “hypertext allows us to write as we think” (42). Bolter argues that hypertext is a remediation of print and as he claims that all writing technologies “participate in our ongoing cultural definitions of self, knowledge, and experience,” so hypertext provides another means of exploring definitions of self and human consciousness (Bolter 189). Given these connections between hypertext and the brain, it is appropriate to examine how hypertextual narratives may reflect on the process of human thought and the experience of consciousness. As hypertext are also associated with the fragmentation of the different pieces of information, applying hypertext to AD, a condition known for the
fragmentation of memories and understanding of selfhood, will provide new ways to approach these AD neuronarratives.

As none of these works are hypertext, I will instead be applying hypertext as a critical theory by looking at works through the lens of hypertext and also viewing these works in relation to hypertext as a medium. These approaches to hypertext can be applied to both printed and electronic works as Bolter argues “it is possible to use print or handwriting to achieve many of the literary or rhetorical effects of hypertext” (40-41). Rather than argue that these works are hypertexts, I will focus on how viewing these works through the lens and medium of hypertext complicate how selfhood and social relationships of AD patients are represented. Landow argues that using hypertext as a lens provides new ways to view a work and may expose aspects of the work that were not seen without this lens (219). David E. Millard and Charlie Hargood in their article “Hypertext as a Lens into Interactive Digital Narrative” explore works through the lens of hypertext, arguing that rather than categorizing a work as hypertextual or non-hypertextual, using hypertext as a lens provides a means to find connections between works and view them differently by revealing “the structural narrative architecture of IDN forms and…the fluidity between them” (Millard and Hargood 12). Viewing these AD neuronarratives through the lens of hypertext complicates the concept of fragmentation of selfhood in neuronarratives as it allows the created versions of the AD patient to exist simultaneously, reveals the networked connections to the AD patients’ social relationships, and connects the complicated shifts in time.

Applying hypertext as a medium to these works also provides a new way to approach these AD neuronarratives. In her article “The Transformation of Narrative and the Materiality of Hypertext,” Katherine Hayles noted the many hypertextual elements in Tom Phillips A
Humument, including multimedia elements such as images and handwriting alongside the printed text. The inclusion of these multimedia elements allowed the inclusion of separate narratives within the main narrative and complicated the cohesive narrative of the work (Hayles 25-26). Though applying hypertext as a medium to comics is under-researched, authors such as Licia Calvi note that comics and hypertext have much in common, making a comparison between them useful. In his argument regarding hypertext and games, Landow claims that applying hypertext as a medium to games is a more appropriate approach compared to approaching games through a hypertextual narrative. The debate about narrative and games in regards to hypertext is discussed in greater detail in Chapter 1. In his article “Games/Hypertext” David E. Millard also utilized hypertext as a medium to approach games, arguing that this approach shows a spectrum of ways to approach narrative and interactivity (124). Comparing these AD narratives to hypertext as a medium showcases the multiple timelines, voices, and multimedia elements in these works. This comparison reveals selfhood to be regularly created by the AD patient through their fragmented selves and through their connections to others. The inclusion of these hypertextual elements complicates a linear reading of the works and combats the concept of consistent degeneration of selfhood leading to the complete loss of selfhood in AD patients.

Methodology And Project Design

The approach for coding multimedia works varies greatly by researchers, and due to this, scholars such as Neil Cohn have critiqued scholarly approaches as being too general. To focus my analysis, I have based by observational theory on Cohn’s approach to comics with a few adjustments. Rather than coding one element across several comics within the same medium, I
code the following elements across different mediums. I used content analysis in order to systematically review the text, images, and interactivity, as well as the work’s overall plot, for the selected works. As I coded these by hand, I focused on a smaller amount of materials; however, the smaller size allowed for more time and detail for each work. I coded all three works in each of the three categories with the following elements: Selfhood, Social Networks, and Affordances and Limitations of the Medium. For Neurogames and Neurocomics, I also included the category of environment as these works rely heavily on images. I also included the category of Agency for Neurocomics and Neuromemoirs as these works provide an outlet for carers, family members, and AD patients to express their experiences.

**Selfhood**

I refer to selfhood as the Alzheimer’s patient’s reference to themselves. For NG and NC, which are created by people other than the AD patient, I focus on the representation of selfhood for the main characters. As NG and NC include images of AD patients, I also include a discussion on how these medium specific affordances describe the AD patient's sense of self. As there are preconceptions that AD limits the AD patient’s understanding of selfhood, I focus on how the AD patients reflect on themselves in NM or how they are represented as understanding their selfhood in NG and NC. This also include flashbacks or memories included in the works as the AD patients must also place themselves in time. I examine how these past representations of themselves impact their perception of selfhood and how they cope with AD as part of this new identity. As NM are the only works written by AD patients themselves, this section will focus on their specific experiences with AD and how they define their sense of self. For all three
mediums, I focus on the concept of fragmentation of self in AD. In this approach, I expand on Pramod K. Nayar’s argument in *Alzheimer's Disease Memoirs* that it is common for AD patients to split themselves into multiple selves. I argue that viewing selfhood in these works through the lens of hypertext complicates stereotypical ideas regarding AD patients in terms of fragmentation and expression of selfhood. I also apply and expand on Lindsay Starck’s stereoscopic metaphor for memory to show how viewing selfhood through the lens of hypertext allows these selves to all exist simultaneously and to complicate the concept of linear deterioration of selfhood.

**Social Connections**

I argue that selfhood is in part only understood by the connections and relationships to others, so the AD patients’ social network is also critical. While AD clearly only impacts the brain of the AD patient, the disease also significantly impacts their friends and family. I catalogue the Alzheimer’s patient’s relationships, including their friends, family, and caregivers, and note changes or difficulties remembering relationships. In NG, I focus on how the narrative introduces the other characters and their relationships to the main characters, even though the game is played through the point of view of the AD patient. In the case of NC, as two of these works are written by carers, I examine how the AD patient’s memories are carried through these relationships and portrayed by their carers. Finally for NM, I focus on how they explore their relationships and how they include their loved ones within their discussion of their lives and their experiences with AD. In all three mediums, these social connections are discussed through memories which complicate concepts of time and can provide multiple narratives within the main narrative. Applying the lens of hypertext to social relationships in these works helps de-
center AD as the main focus of the work. Landow argues that the de-centralizing nature of hypertext makes marginal characters just as important as the main characters within the narrative, which emphasize the social network underlying these narratives. Fraser makes a similar argument that noting these social networks shows the larger impact AD has not just on families, but the community as well. By applying the hypertext lens, I also investigate how memory and time impacts the narrative, the interconnections between characters, and how these elements impact the AD patient’s concept of selfhood.

**Affordances And Limitations Of The Medium**

As modality is a core part of my argument, I focus on the affordances and limitations of the mediums and note similarities and differences between modalities. In his article “Technologies, Texts, and Affordances,” Ian Hutchby notes that affordances are “functional and relational aspects which frame, while not determining, the possibilities for agentic action in relation to an object” (444). Applying this definition to different mediums allows a new way to analyze how technologies are influenced by human interaction both in terms of their creation and how people interact with them (Hutchby 444). The goal of this section is not to rank one work as being better or worse as a narrative, but to describe the ways that modality may impact engagement with the narrative.

For NG, these narratives are intertwined with interactive elements, yet similarly to comics, provide gaps that the player must fill to understand the narrative. A unique property to NG is that they may use aspects of AD symptoms within their gameplay, purposefully slowing the progression of the narrative and requiring the reader to find the appropriate actions to
continue the narrative while also creating a dual narrative where the player has more information than the main character due to the symptoms of AD. I apply arguments from Marie-Lauren Ryan and Astrid Ensslin to approach games as narrative. Though research regarding how AD is represented in games is limited, research regarding comics as a medium is vast, so for the scope of this dissertation, I narrowed my research to focus on comics representing mental health including work from McCloud, Venkatesan and Saji, and DeFalco. While comics are more limited in terms of text, the ability to portray complex emotions through comics is well established and that ability is particularly important in regards to the complexity of emotions surrounding AD. As approaching comics through hypertext is not as heavily researched compared to the other mediums, I utilized research for applying the medium of hypertext to both NG and NC from Landow and Millard. NM are the only works that are directly created by the AD patient themselves and all three authors discuss the writing process within their works and provide first hand accounts of living with AD. I also argue that while it may initially appear as though the literature on print neuronarratives is largely settled, when viewing them through the lens of hypertext, it becomes clear that these works remain in conversation with works in different modalities that may complicate previously understood ideas of representations of AD. As many authors including Bolter, Landow, and Hayles have argued that printed text may be viewed through the lens of hypertext, this approach is appropriate. As my dissertation will only focus on my experiences, this section will only rely on my interactions and arguments regarding the work.

This dissertation aims to compare and contrast these modalities in AD narratives to determine the affordances and limitations of these modalities and how modalities impacts the
representation of AD patients in these works and to argue that neuronarratives should be considered a transmedia genre. NG can utilize images and text, but their gameplay and interactive elements directly impacts the user’s experience of the narrative and they may not have the ability to articulate background knowledge of AD within their game. NC have the benefit of combining images and texts, which allow readers to fill in the gaps between the panels, words and images, and the space between pages as well. NC must clearly articulate their narratives with limited text and their images must be fairly universal for the readers to follow their stories. NM have the benefit of being one of the more traditional forms of literature and allow readers to interact with a handful of characters in a set space, allowing readers to see into the thoughts and mindsets of the characters in a way that is difficult to portray in a two-hour film. However, NM only have text as their modality and they must describe the experiences of their characters clearly for the readers to understand.

Environment

As both NG and NC utilize images and backgrounds for their narratives, I review how these images, page layout, interactive elements, or audio elements depict the characters’ mental states, how they represent AD, or how they represent caring for a loved one with AD. For some of these works, the environment is utilized to describe some of the symptoms of AD or describe research relating to AD including medication and testing to diagnosis AD. Johnson argues in the introduction to Graphic Reproduction, that comics provide a space to discuss what are traditionally considered taboo or uncomfortable topics, so reviewing how NG and NC, works that rely heavily on images, present AD and the aging body is appropriate. This discussion also
includes how memory and time are represented and how this impacts both the AD patients and their friends and family members. For NG, I also include discussions of the audio and interactive elements alongside the images and backgrounds. For NC, the impact of the page layout and panels is discussed in detail as well as the gap-filling required between panels and pages. Though approaching comics through the medium of hypertext is under-researched, both George Landow in *Hypertext 3.0* and David Millard in his article “Games/Hypertext” support this approach for games. Viewing these works in terms of hypertext as a medium emphasizes the gap filling and interaction between the reader or player and the narrative.

**Agency**

As many AD patients feel helpless and unable to have any control over their lives after their diagnosis, I focus on how these mediums allow AD patients or their loved ones regain a sense of agency through these works. As the NM are written by the AD patients and the NC are written by authors with experiences caring for AD patients, this category will only apply to these two mediums. While NG may provide a means for raising awareness about AD itself, both NC and NM provide a direct discussion of agency and reflect on the experiences of AD or caring for an AD patient. Agency is particularly important to AD neuronarratives as it provides an opportunity to discuss the impetus for writing these works, but also on the impact of writing to re-establish selfhood after an AD diagnosis. Tougaw argues that restoring a sense of agency is essential to neuronarratives and also provides a means of reaching out to others to express these experiences. I also apply Hayles’ argument regarding materiality of hypertext and how these characteristics of hypertext break the reader out of the narrative to connect to outside events.
Viewing agency through the medium of hypertext provides a new means of viewing the multimedia elements of the works, the connections to organizations or events outside of the narrative, and continues to complicate the concept of selfhood as the AD patient seeks to understand AD and cope with the neurological changes.

**Chapter Summaries**

The remaining chapters are organized in the following way:

Chapter 1: The first chapter focuses on neurogames about Alzheimer’s Disease: Forget Me Knot (2020), Alzheimer’s Memories (2021), and Before I Forget (2020). These neurogames are narratively driven and have an AD patient as the main character. Though representing AD is at the core of the story, these narratives push back against the stereotype that AD becomes the only important part of the character, and through narrative, re-center the story to focus on selfhood and the main character’s social relationships. The interactive elements and how they relate to the narrative and how they represent AD are examined for all three games. Approaching hypertext as a medium with these games emphasizes the gap-filling required by the player as they developers purposefully slow and complicate the narrative as a means to represent AD symptoms. Rather than viewing these as serious games, games that are designed for educational purposes, focusing on the narrative and representations of AD provides a space for players to question their own perceptions and stereotypes regarding AD and view the AD main character as a person rather than just their illness.
Chapter 2: The second chapter focused on print neurocomics: Roca (2007 translated to English 2016), Walrath (2016), and Levitt (2012). These neurocomics describe the experiences of caring for a person with AD. While Roca’s work is a fictional piece, it was created through the combinations of several real events and has been praised as one of the first comic representations of AD. Both Walrath and Leavitt describe their experiences as carers to their mothers, revealing both the enjoyable and devastating aspects of AD. I review these works through the representation of selfhood, social interactions, and environment. Particular attention is paid to the expressing of bodies that are aging or ill as these comic present the realities of caring for AD patients. These works all incorporate aspects of fantasy to balance the painful reality of the disease, but these works combat stereotypical images of AD through directly confronting these realities. While these AD patients will pass from their disease, these works also emphasize that the AD patients are never truly absent, even in the late stages of the disease, and that they are carried on through the memories of their loved ones.

Chapter 3: In Chapter Three I selected three print neuronovels (Mitchell (2018), Saunders (2017) and Gibbs (2021)) and focus how these neuronovels complicate the concept of selfhood through what many consider a more traditional means of narrative. These works complicate the idea of a stagnant sense of selfhood to one that is constantly changing through the multiple versions of self that the authors create. Though initially appearing to be straightforward linear text, viewing these works through the lens of hypertext and noting the hypertextual elements within the works complicate their structures and create multi-linear texts that incorporate multiple voices, timelines, and selves to express their experiences with AD. I review how each
text addresses selfhood, social connections, and agency in response to their AD diagnosis and the changes that AD has imposed on their lives. While these works may appear to be limited due to their lack of range and interactivity due to their print medium, these works allow a unique affordance of providing a means of people with AD to express themselves and describe their own experiences with limited assistance or outside voices speaking for them.

Conclusion: My final chapter will primarily focus on comparisons between the three modalities, focusing on the affordances and limitations of these mediums. The importance of materiality in research or comparing mediums and how viewing these works through the lens and medium of hypertext are discussed to support the argument that neuronarratives should be considered a transmedia genre. I also discuss why these narratives are important and how their ability to communicate information about Alzheimer’s Disease through narrative is useful. It ends with suggestions for future areas of research in the field.
CHAPTER 1: I SPY A MEMORY: NEUROGAMES AND ALZHEIMER’S DISEASE

Introduction

Using games to represent or explore a character’s mental state provides a new means of exploring the experience of consciousness, especially for conscious experiences that are impacted by diseases or mental conditions. While there are many incredibly well-made games, for the scope of this paper, I will be centering on games that focus on mental health, which I will refer to as neurogames. These are games that focus on neurological conditions where players play as either the patient themselves or alongside them and are developed for educational or entertainment purposes. While this term has not been used in scholarly research, using digital media to explore consciousness is not a new field of study. Marie-Laure Ryan argues in *Avatars of Story* that as humans are programed to be natural storytellers, the use of technology, such as interactive fictions, either “imposes its possibilities and limitations on the user” (Ryan 27). This implies that readers use affordances such as animation or interactivity to move through the narrative or they work through these limitations or ignore them to progress; regardless, the medium impacts the process of reading the narrative (Ryan 27). This paper will focus on the medium of games for expressing the condition of Alzheimer’s Disease, but I will first review a few examples of neurogames.

Games about mental health are not limited to independent, or indie, developers, but can be successfully created by AAA games such as *Hellblade: Senua’s Sacrifice* by design studio Ninja Theory in 2017. *Hellblade* developers coordinated their work with research from medical professionals to attempt to allow the player to experience psychosis and to also battle stereotypes
surrounding psychosis through the gameplay (Fordham and Ball 3). Gameplay was directly influenced by the symptoms of psychosis as both narrative elements and puzzle elements relied on hallucinations and delusions (Fordham and Ball 7). Neurogames like *Hellblade* are critical as they “can provide new forms of embodied experiences, which may help to promote empathy and awareness of mental health issues” (Fordham and Ball 10). Jodie Austin points out that while it can be difficult to represent mental health in video games, the way in which psychosis is presented in *Hellblade* may help players “better understand and empathize with the experience of psychosis.” For Austin, *Hellblade* is impactful due to its “…medium that, by definition, actively subverts distinctions between reality, fiction and personal agency,” though she acknowledges that representations of mental illness in video games remains a challenge for many game designers. Meakin, Vaughan, and Cullen emphasize the importance of distance between the player and avatar through their application of Aristotle’s *Poetics* to *Hellblade*. They argue that through distance, the player is made aware that the hallucinations that Senua is experiencing is her perception of reality, while the player is privy to the actual events in the environment as well. Through this distancing, *Hellblade* “presents a narrative that uses the very materials of mimesis and distancing to produce layers of meaning, exploration and emotional illumination” (Meakin, Vaughan, and Cullen). *Hellblade* is a prime example of how a character’s mental state can be expressed or represented in a game.

While games such as *Hellblade* focus on the addition of symptoms through psychosis, other games such as *Ether One*, created by White Paper Games in 2014, focus on the loss of sensations and memories as the narrative focuses on patients with Alzheimer’s Disease (AD). In *Ether One* the player gathers a collection of objects in order to restore a woman’s memory. As
Michael Thomsen notes in his review of the game in the *New Yorker*, the problem with this game mechanic is that it oversimplifies AD and suggests that patients of AD are blank slates that can be filled in rather than a waxing and waning process where patients may have long durations of complete lucidity until the illness progresses. The developers responded to these claims by pointing out that they were not intending to raise awareness about AD, but rather make an interesting game with restoring memory as part of the narrative (Thomsen). This is a critical point as not all games are required to be accurate or mindful of their representations. The developers may want to focus on an interesting narrative and gaming experience for the players without focusing on a message or working with outside researchers to inform their gameplay or narrative plot.

The focus of this paper will be on the following three games: *Forget Me Knot*, *Alzheimer’s Memories*, and *Before I Forget*. These games allow the players to play as a character with Alzheimer’s Disease and experience the developer’s interpretation of the disease. These games have a variety of scientific background as *Forget Me Knot* was created with the goal of raising awareness of AD and *Before I Forget* was designed with the consultation of neurological researchers, none of these games have an explicit goal of educating the player on AD. However, these games emphasize empathy and complicate the idea selfhood through a mix of game play and the character’s dialogue. *Alzheimer’s Memories* has very limited dialogue, but uses the concept of dreams to explore the main character’s experiences. Through the gameplay, while AD remains a key aspect of the narrative, these games highlight the character’s past rather than focusing entirely on the disease, preventing the character to be defined solely by their AD. Viewing these games through the medium of hypertext, shows that the player must make several
connections between the visuals and gameplay, the characters’ dialogue, and filling in the gaps of the narrative due to the character’s lack of memory. These neurogames mix genres combining mystery and object finding games with the character’s social relationships and past. Through the game mechanics, the player can also see how this condition impacts the rest of the character’s life and gain empathy for frustrating and terrifying aspects of the condition.

**Games And Narrativity**

It is important to note that while these neurogames focus on mental health or neurological conditions, they are not serious games, or games that are designed for educational purposes. Though some of these games were intended to help raise awareness about AD, these games are clearly more narrative-centered. Games Studies is a large and well-established field, so for the sake of brevity, I will only provide a brief overview of the ongoing debate the application of literary criticism and theory to games and digital media. While this is a large and on-going debate, for the scope of this paper, I will focus primarily on the arguments of Espen Aarseth, Astrid Ensslin, and Marie-Laure Ryan in regards to the relationship between literature and ludology and how medium impacts the application of critical theories to games.

In Espen Aarseth’s article “Genre Trouble” (2004), he argues that “Games are not "textual" or at least not primarily textual.” While Aarseth notes the similarities in narrative for adventure games, he argues that the gameplay and narrative are at odds with each other as players may lose track of the story through the game mechanics, may choose not to care about the story in preference to the game mechanics, or may choose to abandon the game without completing the narrative (Aarseth “Genre Trouble”). While many scholars, such as Astrid
Ensslin and Marie-Laure Ryan, have combined ludology, the study of games or play, and narratology to approach games, Aarseth argues that the current approaches are still not appropriate to view the narrative elements in games. In his more recent article “A Narrative Theory of Games” (2012) presented at the International Conference on the Foundations of Digital Games, he proposes a new model that uses as “ludo-narrative designspace as four independent, ontic dimension” which include: world, objects, agents, and events (Aarseth “A Narrative Theory” 129). Though Aarseth acknowledges the importance of narrative theory, he still disparages authors such as Ryan and Ensslin for their theoretical approaches towards ludo-narratological approach for games.

Marie-Laure Ryan’s argument in Avatars of Story presents a spectrum of literary and ludic characteristics of games and she emphasizes the importance of the medium for narrative. While Aarseth and the ludologist school views games and narrative as separate, Ryan argues “…that the major contribution of the digital medium to games is to have made strategic play compatible with make-believe and imaginative participation in the fiction world” through narrative (xxiii). Her argument finds a middle ground between Aarseth’s argument that games and narrative are inherently separate and the other extreme that everything must be considered a narrative. In part, this middle ground is based on the core argument that narrative is “a cognitive construct,” but that the construct can be created in many different ways, what she refers to as “modes of narrativity” (xix). Ryan argues that part of the difficulty with narrative studies is the wide variety in definition of what constitutes both a narrative and a medium. Adding to this debate is fact that “the difficulty of reconciling narrativity with interactivity” is “the most distinctive property of digital environments” (Ryan xxiii). For Ryan, the only way to address this
problem is to empathize the medium of the narrative and have the narrative adapt to the properties of that medium (xxiv). Though still limited in the range of what may be included as a narrative-focused game, Ryan’s argument emphasizes the importance of the medium as more than just a vehicle for the narrative.

Astrid Ensslin’s work *Literary Gaming* is an expansion of Marie-Laure Ryan’s argument. Ensslin argues that “Literariness in the sense of twenty-first-century verbal art opens itself to an ever-changing array of interactive and multimodal practices” and due to this wide variety, “there is no one way of reading digital media” (6). Ensslin uses the term “literary gaming” to provide a category for hybrid works (Ensslin 6). She defines literary gaming as a type of game that combines literature and ludic characteristics (Ensslin 1). Works that fit under this title are hybrid works that combine “both readerly and playerly characteristics” (Ensslin 1). Similarly to Aarseth’s four categories, Ensslin creates a spectrum to view these works to note their literariness or ludic characteristics. Unlike Aarseth, Ensslin argues for a wider definition of ludic in print works and explains that, “digital literacy must involve the aptitude, ability, and willingness to adapt our interactive practices to every individual artifact…” (6). By focusing on these similarities, Ensslin argues it is appropriate to expand both literary and ludic approaches to video games while still clearly acknowledging the differences in medium. Though Aarseth raises valid concerns over the generality of terms and the problems of lacking a clear theoretical backing, this paper supports Ensslin’s and Ryan’s approach towards expanding how narrative theory and ludology to include more mediums such as games provides new approaches to these works.
Another important approach to games is through cognitive frameworks. Katherine Hayles argues in her article “Hyper and Deep Attention: The Generational Divide in Cognitive Modes,” that there is an ongoing generational shift in cognition styles seen in the divide between hyper and deep attention (187). Hayles summarizes deep attention as the more traditional means of focusing on one object for a long period of time compared to hyper attention which is associated with multiple tasks and rapid shifts between tasks (Hayles 187). Ensslin breaks down Hayles’ deep and hyper attention and argues that literary and art games are different from larger mainstream games as they immerse players “without fully suspending disbelief or developing a permanent state of hyper attention” (39). Instead, playing these games requires the player to choose one style to approach the game to “either play the game successfully or close read it to comprehend its literary forms and meanings” (Ensslin 39). For Ensslin, the player’s awareness of their approach to the game will also cause the player to reflect on their expectations, to confront the coded ideologies within games, and explore the player’s own playstyle and preferences (Ensslin 40). While exploring these particular cognitive approaches to games is not within the scope of this paper, this research reveals the benefits of exploring mental health within games as a means to explore different representations of mental health conditions and providing a space for players to reflect on their preconceptions and experiences.

**Hypertext And Games**

As this paper views neurogames through the lens of hypertext, another important debate that must be address is the validity of the relationship between games and hypertext. In *Hypertext 3.0*, George Landow reviews the debate about genre for games and how they may be viewed in
relation to hypertexts. Though he agrees with Aarseth’s concerns about overlapping genres, he takes a less extreme route towards video game narratives. As Game Studies is now its own field of study, Landow argues that “… the most useful point of comparison is instead to hypertext as a medium and not to hypertext narrative” (Landow 250). This approach is supported by David Millard in his article “Games/Hypertext” from the 31st ACM Conference on Hypertext and Social Media. Millard views the link between hypertext and games as a “… spectrum of interactive narrative experiences” and viewing games and hypertexts together will “reveal commonalities, and show why game design, interactive fiction, and hypertext theory should be linked” (Millard 124). Viewing these AD neurogames through the medium of hypertext complicates the concept of fragmentation and loss of selfhood within these representations of AD. Rather than viewing these games as hypertext, by viewing them in terms of their hypertextual characteristics, the concept of fragmentation of selfhood, the social relationships between characters, and the impact of the game’s environment provide novel ways of representing AD in games.

Traditionally hypertext is associated with games or interactive fiction that provide multiple pathways and endings, however, Ryan argues that if digital narratives provide endless endings and pathways, they can create confusion and may not be enjoyable nor comprehensible (125). With neurogames, the narrative is critical for the game, so the games discussed in this paper have single endings. However, Millard argues that “even games that appear to be linear can contain hypertext elements” (Millard 125). On the surface, these short single ending AD neurogames, may seem straightforward; however, through their unique structures and interactive elements, these narratives utilize their medium to create unique representations of AD. In her
work *Wandering Games*, Melissa Kagen breaks down and complicates walking simulators, an often disparaged genre. Though on a much smaller scale, these three neurogames also utilize wandering as a means of exploration, both of the physical location and of the memories and mind of the main character. This game mechanic forces the player to move more slowly and learn more about the main character as a person, rather than just an AD patient. So, while there is only one actual ending to each game, this process of exploration introduces multiple characters and timelines, which complicate the linear narrative.

The balance between narrative and interaction is a key aspect to all three games. Ryan argues that characters that have more depth and “undergo truly poignant experiences” typically have the player as more of an observer than active participant in the narrative (125). This is the case in all three games, as the player is able to interact with different items that prompt the character to speak, the memories clearly belong to the character and the player is meant to observe and understand. However, the active role of the player comes in making the connections between the objects and memories and the provided information in the game. For all of these games, the player must take an active role in understanding and connecting these memories or objects together to help create the narrative. Aarseth argues that while novels “are very good at relating the inner lives of characters...games are awful at that” ("Genre Trouble"). While he does acknowledge that games focus on the self, he argues that only multiplayer games can address interpersonal relationships ("Genre Trouble"). Meakin, Vaughan, and Cullen argue that *Hellbalde* allows the player to relate to the “character’s inner life” in a “specifically game-based way.” I argue that these three AD games not only allow the player into the inner life of the AD
patient, but also explore their relationships to others in a unique way through the interaction of the player and the gap-filling process required to move forward in the narrative.

**Forget Me Knot Summary**

Gap-filling is critical to the narrative of *Forget Me Knot*, a short game created by Scottish game developer Alexander Tarvet. This game was originally created as a student project with the goal of raising awareness about AD. The short game takes place in a single room and the player interacts with their environment through an elderly man named Harold. The game begins when Harold wakes up, slightly disoriented, and looks around the room. The player can interact with a variety of objects and Harold will respond with dialogue. These moments of dialogue are not interconnected and seem to represent his inner thoughts as he moves around the room. However, Harold doesn’t always have the ability to identify the people in photographs or understand why there are sympathy cards on the mantel. Through the interactions with the various things in the room and voice messages left by Harold’s daughter on the answering machine, the player is able to piece together the basic events. Harold’s wife has recently passed, and his daughter Izzie is coming by the next day to join him in spreading her ashes. Once the player has interacted with everything in the room, a bright blue handkerchief will appear on the table. Picking up the handkerchief results in Harold’s daughter calling again, reminding him that she is coming in the early morning and pleading with him to remind his carer and write down the message, so he doesn’t forget. He is unable to write the message and instead falls asleep in his chair, ending the game in the same way that it began. This game requires players to actively explore the room to
gain insight into Harold’s life, but the players are ultimately unable to completely fill in all the gaps due to Harold’s AD impacting his memory.

**Selfhood In Forget Me Knot**

While the player interacts with the objects in the room, they can learn more about Harold and construct his identity and past, but his lack of information complicates this process and the player must fill in the gaps to understand Harold and get some background information on him. Though the interactions with the various objects, the player is able to get a better understanding of Harold, though there remain several gaps as the player can only move within the room and interact with certain objects. In an article describing the relationships between Virginia Woolf’s *Mrs. Dalloway* and Ian McEwan’s *Saturday*, Lindsay Starck uses the metaphor of a stereoscope to describe memory. A stereoscope is a tool that combines two versions of the same picture together to create a new, more detailed image. By applying this metaphor to the concept of selfhood, Starck argues that “the presentation of the two selves, the two images, the two realities side by side that creates depth and meaning by establishing connections between them” (Starck 338). As AD patients experience progressive neurodegeneration, applying Starck’s argument helps provide a means of combining and keeping these senses of selves apart. However, unlike Starck’s dual selves, AD patients have many selves, so perhaps a kaleidoscope is more appropriate than a stereoscopic as the patient’s cognition is altered with every version of self either due to age or progression of the AD, but all still belonging to the same individual and, at least in the early stages of AD, still able to retain some awareness of the other versions of themselves.
Applying this approach to *Forget Me Knot*, reveals the various pieces of Harold’s selfhood exist through these objects and the player is the one that must put these pieces together due to Harold’s memory loss. Harold’s own inability to recall the names and details about several objects further complicates the ability of the player to understand him as a person. Ryan argues that narrative can use the medium “purely as a transmission channel” of information or “can actively fight some of the properties of the medium for expressive purposes” (30). Applying this argument to Harold’s past is particularly interesting as the player cannot trust Harold as a narrator as he doesn’t remember his past; however, without an omniscient narrator and with no other outside information except for the game description, the player has to make decisions themselves to create an identity for Harold. While the game is providing pieces of information on Harold’s past, Harold’s limited dialogue and lack of other context clues limits the ability for the player to understand everything in the room.

Through the interactivity of the game, the player is able to gain some information on Harold, occasionally aided by the character himself. While the player never sees what Harold looks like, there are photographs on the mantel of a family, a young man graduating, and a child with a stuffed animal that appear to be his family. The player can click on the photographs, but Harold is unable to remember who these people are. There is also a wedding picture beside these images on the wall, but while Harold acknowledges them as a “handsome couple,” he still cannot name them or why they would be on the walls. The player can assume that these are pictures of a younger Harold and his family. This can be gleaned due to the inclusion of these images in the living room. Aarseth argues that “In hypertexts, it is always nonlocal, that is, we don’t know exactly what to look for or where to link. In games such as *Adventure*, the aporia is local and
tangible, usually a concrete, localized puzzle whose solution eludes us” (Aarseth 124). *Forget Me Knot* is an example of a hybrid of both approaches. The player is limited in the location of where they can explore and there are no alternative pathways that result in a new ending; however, as Harold is unable to fill in the gaps of the object’s history and the objects that prompt responses from Harold do not appear any differently than the non-interactable objects, requiring the player to click and attempt to interact with everything in the room to try to gain an understanding of who Harold is and how these objects relate back to him. Harold’s lack of memory requires the player to actively fill in these gaps as best as possible, but some gaps must remain as Harold only responds to some of these objects with a clear connection to himself.

By applying the definitions of Carstensdottir et al., these interactions combine progression through discovery, which is where players must “locate story content in order to progress through the story” and progression through scripted scenarios which “requires the player to follow a pre-scripted series of action” (Carstensdottir et al. 4). This mix of agency and listening to scripts may leave the player feeling frustrated as even with all the information provided through the game, there are inevitably gaps that the player is unable to fill and that Harold is unable to recall. This need to supplement information supports Ryan’s argument that narrative within games still allow for “imaginative participation in the world” and allow players to incorporate their own ideas and assumptions into the game, while still following the plot (Ryan xxiii).

The game also shows Harold’s awareness of his memory loss, but shows his inability to compensate through memory tricks. In the note, Harold mentions the handkerchief he had knotted to remind himself of something, but is unable to remember what the knot was for. This is
a reference to the title and the handkerchief appears on the table towards the end of the game. The sudden appearance of the handkerchief could be linked to visual neglect, a syndrome some AD patients struggle with when their brains do not perceive objects, even when it is right in front of them (Vasquez et al. 1748, Kasai et al. 379). This detail may seem small, but it shows how gameplay can reflect actual aspects of the disease. This note also suggests that Harold is trying to use notes as a reminder. There is a stack of paper beside the typewriter that has text on it, but the player is unable to click on it or read it. His daughter also references the note taking in her message, suggesting that Harold is just starting the practice or is struggling to keep doing it consistently. Similarly to Meakin, Vaughan, and Cullen’s argument that distance allows the player to see both the perspective of the character and a distanced perspective in Hellblade, Forget Me Knot allows the player a similar dual perspective. The player can pull these different pieces of information together to understand that Harold is somewhat aware of his memory problems, but is unable to correct them himself and his previous attempts are not very effective. This may also provide some insight into the stage of his AD as visual neglect or visual simplification often occurs in the later stages of AD (Vasquez et al. 1748, Kasai et al. 379). However, the medication description found in the provided medical book of the game, indicates that the medicine is for the early stages of AD, so this mechanic can be directly related to symptoms or may be a way to require detailed interactions from the player before the narrative continues.
Social Connections In Forget Me Knot

Though the player only interacts with Harold, the other people in his life are clearly connected to the narrative and utilize interactivity to be included in the game’s narrative. In Harold’s notes, he describes a “nice young woman with the small children” who “looks remarkably like my wife Mary,” but clearly doesn’t connect that this person is his daughter. He also questions why Mary has been gone out for shopping for so long. The passage of time is unclear in this game. There is a clock on the wall showing that the game starts at midnight, but though the clock continues to click, there is no change in the time depicted. As there are no dates provided on the notes, nor any newspapers or other time references, it is difficult to understand how much time has passed since Mary’s death. However, the player can infer that her death was recent due to the sympathy cards remaining on the mantel and with his daughter calling about spreading her ashes. This game requires the reader to make these connections as Harold is unable to provide the missing pieces of information.

The game utilizes audio clues as well as visual clues to help the player gather information on Harold and the current events. There is a blinking answering machine and the player can click on it to hear a message from Harold’s daughter Izzie. As Scott Rettberg argues in *Electronic Literature*, hypertext utilizes “a multi-threaded approach” as a core characteristic of hypertextual storytelling, so including this phone call into the game allows the players to see the wider impact of Harold’s AD and to gain some insight into other events outside of the game (57). Izzie is clearly frustrated with Harold as she calls for him several times, makes an annoyed noise, and complains that Harold calls at all hours of the day and night, but it not picking up the phone. She claims that she is going to come over to him, but calls again later in the game and chooses to
come in the morning instead. The reader can assume that this is the nice woman who looks like Mary, because she also has young children you can hear in the background. This brief message, as Harold never responds to Izzie’s comments during the phone call, also provides an insight into the difficulty of being an adult child to an AD patient. Izzie has young children to care for and it is clear that between mourning her mother’s passing and trying to cope with her father’s AD has caused significant stress in her life. Even when she tries to be supportive and optimistic, her daughter Karen interrupts the phone call and Izzie has to return her focus back to her child. Her frustration paired with her belief that her father could write the notes and use them, suggests that his AD has only recently become more significant. This is supported by the information provided in the medical book which will be discussed in the next section. As there is no omniscient narrator, the player has to pull all of these pieces of information together to understand their relationship.

As the creator notes in the description of the game, this feeling of confusion is purposeful and designed to allow the player to gain an understanding of what it is like to have AD, a unique experience that the medium of games allows. By purposefully making gaps within the narrative that the player will never be able to fill, this game can provide a representation of the mental state of AD patients. The player does have the advantage of being able to retain this information, so while there will be gaps in information, Harold remains the only one unable to understand the events. After Izzie reminds her Harold what’s going to happen tomorrow, Harold’s lack of response to her and his immediate return to focusing on the dog that is likely deceased, shows his complete disconnection to the phone call. This could also be another connection to AD patients’ struggle with listening to phone conversations rather than face to face conversations.
(“Communicating and Dementia”). This was something that was mentioned by the authors in Chapter 1 as they often would switch out phone conversations to face-to-face meetings or through a video phone call to help connect the voice to the person.

While Izzie is a key character, she is not physically present and neither is the other key character, Harold’s wife Mary. Despite the fact that she has passed away, there are physical reminders of her in the game. While Harold may not understand the wedding photo or the condolences letter, he recognizes the watch. The inscription reads, “Happy anniversary Harold. I love you with all of my heart.” While he doesn’t mention her by name when the player interacts with the watch, he does comment on how quickly time flies by and seems nostalgic. This object is also important as it is the only one that names Harold. If the player did not read the description of the game, this would be the only indication that he is named. At the end of the game, Harold does specifically reference Mary, but in a rather tragic way. After Izzie hangs up, Harold sits down and falls asleep. He wakes up and looks at the cards on the mantel, but rather than remembering that they are sympathy cards for the loss of his wife, he assumes that they are for his birthday. He is happy about this because Mary always bakes him a cake for his birthday. The player understands that Harold has no memory of the game’s events nor that his wife has passed, but while the loss of his memory is devastating, in Harold’s mind, Mary is still alive and will bake him a cake and he doesn’t have to experience the impact of her loss. Despite Aarseth’s claims in “Genre Trouble” that games cannot show interpersonal relationships, *Forget Me Knot* emphasizes the impact of AD on the family dynamic, while also complicating the idea of fragmentation. While Harold cannot maintain his memories connecting to many objects in the
room, his love and devotion to his wife is clearly expressed through his memories of her, even ones that are incomplete.

**Environment In Forget Me Knot**

Compared to the other games in this paper, *Forget Me Know* has the least amount of space for the players to explore; however, through interactivity, the game is still able to provide the player with information to help them understand the plot of the narrative. While Harold is confused about some of the photographs and is unable to identify the people in them, other objects are more familiar to him such as the war memorial. He comments that the “Jerry boats” were never-ending, indicating that he was a WWII veteran. This is a useful example for the player to understand how Harold may be able to remember his service during WWII, but struggles with recognizing photographs and names of his family members. Interacting with the environment shows the player that Harold doesn’t have complete memory loss, but is clearly impacted by his condition.

The only distinct mention of AD is found in a medical book on the floor which explains basic information about AD and a medication called Donepenzil. In the book, only the text about the medication is easily readable. The text describes Donepenzil as a medication for the early stages of AD and it is intended to slow memory loss and decrease the risk for aggression and delusions. Kumar, Gupta, and Sharma state that while Donepenzil does not prevent the progression of AD, it can help “ameliorate the symptoms.” The image of the drug is also important as the player can match it to the bottle and pills spread out on the side table. Regardless of the order in which the player interacts with the book or pill bottle, Harold does not
make any connection between the two items. He has no comment when the player picks up the book, but there is a distinctive folded corner on the book, suggesting that someone had found this section and marked it for later reference. This knowledge about AD and the fact that Harold is being treated for AD symptoms is one clear example of the player having knowledge that, while Harold has, is not able to retain or utilize to understand that this medication is his and is being used to treat his AD. One of the benefits of viewing this game through the medium of hypertext is the ability to both separate these fragmented pieces of information and also connect them to the overall plot. Landow argues that hypertext removes the “linearity of print” and in the gameplay of *Forget Me Knot*, the player has no real order they are required to follow to interact with the objects and there are no specific dialogues or changes if the player interacts with items in different orders or if they interact with the same object multiple times (99). The only object that signals the final stage of the game is the blue handkerchief which starts a cut scene that the player cannot control. The second phase of fragmentation, according to Landow, happens when the player tries to fit the pieces back together in relationship to other endings or other possibilities (99). There are distinct gaps that the player must account for to complete *Forget Me Knot*’s narrative.

While *Forget Me Knot* is a short game with limited environment, through the utilization of the interactive elements, the player is able to gain an understanding of what living with AD might be like. While through gameplay, the player is ultimately able to make the connections that Harold is unable to, there remain several gaps in the narrative that the player must fill themselves and some that the player is not able to fully answer. While Harold is the only character the player interacts with, through the interactivity of the game, the player is able to
learn about the other characters and their relationship to Harold. The cyclical structure of the gameplay is particularly powerful as AD patients struggle to retain any short-term memory, especially late at night, so this reset is a useful structure to have the player experience this, even though they retain the memories of playing the game. The collection method of gather memories is something that is utilized in the other games even more clearly.

**Alzheimer’s Memories Summary**

The game *Alzheimer’s Memories* by Gillian Yue is the most abstract of all three games. This game takes between forty minutes to an hour to complete. The game begins with the main character explaining through text that he is an old man who has been diagnosed with AD. The character is never named and there is no narration or description of who he is on the creator’s page. In the introduction to the game, the player is told that he doesn’t struggle with day-to-day life as he has a simple routine and lives alone, but he is upset because he doesn’t want to forget things. He explains that he has trouble sleeping, so he uses sleeping pills and they make him dream. The text ends with “time to sleep” and implies that he has taken the medication. This sets up the gameplay with the understanding that the player is seeing the man’s dreams. Dreams are particularly important for Yue, as the creator comments that, “dreams are forgotten bits of your past clinging on to you” and that the dreamer “has to make sense” of the dreams and make connections that may not be clear.

With no narrator and no other text putting the scenes into context, these connections fall almost entirely to the player, forcing them to actively engage and connect these vignettes to the man’s life. This game uses a point and click style of interaction and the order that the players
click on objects does impact the progression of the narrative in that everything that is interactable must be clicked on before the scene can progress and some must be clicked in a certain order, again combining progression through discovery and progression through scripted scenarios (Carstensdottir et al. 4). Ironically, in a game about a man with AD, there are several memory games such as one that requires the player to recreate melody by clicking on different colored notes in the correct order. Millard argues that applying the MDA (Mechanic, Dynamic, and Aesthetic) approach to games allows the player to create the narrative and creates an interaction closer to reading (Millard 124). In this case, the player is following the different transitions into each scene, following the patterns of music to solve the puzzle, and regaining a sense of agency as their interactions leads towards the narrative progressing.

Selfhood In Alzheimer’s Memories

Selfhood in Alzheimer’s Memories is the least clear of all three games discussed in this chapter due to the limited narration and dialogue from the main character. The fact that no one is named makes selfhood even more limited; however, the personal moments of these memories do provide some input into who this character is and why these memories are special to him. As Yue argues that dreams are memories, the player is getting snapshots of the character’s life and the key people and pets involved. This is the only game that directly states that the main character has AD and begins the game with this information. While the character is not terribly familiar with AD, seen in his comment “apparently it [Alzheimer’s Disease] makes you forget things,” this is the only game of the three discussed here where the main character is aware that there is a problem with his memory and that he has been diagnosed with AD.
The focus on the character’s dreams shows how the medium of games can be utilized to present this information as watching someone’s dreams makes perfect sense in a game, while it would be impossible or less concrete to imagine these abstract visions in print or static images. For Ryan, a medium is only “considered narratively relevant if it makes an impact on either story, discourse, or social and personal use of narrative” (25-26). As the gameplay takes place in dreams, the sudden shifts in time, transitions between characters, and even the player’s interaction with objects works and creates a stream of consciousness style narrative. The character’s AD can also account for the lack of dialogue and unclear understanding of time passing as well.

The player has to take an active role to understand the events of the narrative and to gain an understanding of the main character. Though it initially appears that the scenes follow some chronological order as the main character’s appear small at first, the scenes quickly flicker between a child breaking a vase and an older person breaking a vase, shown in the size and shape of the hands changing. These shifts show how the main character is flowing back and forth between the past and present with the separation of time unclear in the dreams. Viewing these shifts in terms of different versions of selves, this again complicates Starck’s idea of stereoscopic perspective of past and present. Similarly to Forget Me Knot, viewing the main character’s sense of selfhood as a kaleidoscope shows how these shifting selves still link back to the main character’s sense of selfhood as he re-inhabits his older self during these memories, but occasionally remembers his actual body which either simply integrates into the memory as everyone else remains young, or interrupts the memory, causing the scene to change. This shifts in time are difficult to follow as there is no clear temporal clues from the environment or
gameplay. While it is clear that both *Forget Me Knot* and *Alzheimer’s Memories* take place in a single evening, the range of events that the main character remembers in his dream stem from a childhood memory to one with a carer, which complicates any sense of time. Also, as the character provides no narration or commentary on the events, the character’s sense of selfhood must be made by the player as they interact with these key people and moments in the main character’s life. The player must actively engage in the interactive elements to move the plot forward, but they are also responsible for creating a clear, or as clear as the plot allows, timeline.

The character’s hands are a critical part of determining the timeline as the main character is only shown once. As the character is not revealed until the final scenes of the narrative, these changes in their hands’ appearances are the only reminders to the player that the main character is elderly. A clear example of this disjointed sense of time comes towards the end of the narrative when the main character offers the young woman a flower. The first part of the sequence shows the young main character picking the flower and walking towards the young woman, who’s not looking at him. However, by the time that he reaches her and offers the flower, his hand has become wrinkled and more curled compared to the previous image. The main character is the only one in these memories that has any aging. All of the characters, even the ones who appear to be his family members, never age from the way they are presented. The final scene shows the image of the man, with his most detailed wrinkled hand in the entire game, reaching for the un-aging young woman again, without the flower. This constant reaching suggests his consistent yearning and affection for her that has remained. However, there is a clear reason why she has never aged in these memories; she died years ago and this is how he remembers her. As Landow argues that hypertext disrupts the narrative, viewing *Alzheimer’s Memories* through the medium
of hypertext showcases the fragmentary nature of AD. The lack of aging for any of the characters compared to the main character and their lack of finality or completion of the narrative forces the reader to take an active and participatory role in the narrative.

Social Connections In Alzheimer’s Memories

The unnamed young woman is one of the most important characters in *Alzheimer’s Memories*, but the player has even less information about her than about the main character. In a mini game where the player throws toys or sticks for the main character’s dog to fetch, the game is interrupted by the young woman petting the dog. There is a quick transition where the main character is holding a flyer for an art exhibit, but they never enter the museum, but play hide-and-seek. The player must keep switching between different parts of the environment to find where the young woman is hiding. As the game continues, the garden becomes more colorful, and more things become interactable. These changes in the environment connect to the main character’s feelings towards the young woman; the world seems brighter when they are together, which is something they player can understand through these changes, rather than needing an explanation. The garden game ends with the young woman wearing the flower in her hair with an Art Nouveau style. While this is the least descriptive version of her actual body, the detailed background clearly connects her to both flowers and art, representing the earliest memories the main character has with her. These scenes also combine music as another means of expressing emotion. The choir music in this scene creates an almost otherworldly atmosphere to her, signifying her importance to the main character. Ryan notes that while music may be limited in
expressing specific thoughts or dialogue, its strength is in the ability to convey emotions (Ryan 19-20). Again, the player must make all of these connections and assumptions without any
dialogue or narration, requiring them to take an active role in not only understanding the plot, but
making connections between the art styles and body changes of the characters.

The game utilizes brief vignettes to show the development of their relationship and to
also acknowledge the passing of time without providing any dates, calendars, or clocks. The two
characters interact with each other in what appears to be their shared home, which indicates that
they have been together for some time. However, this image is one of the most important of the
young woman, because this image, and similar variations, are shown of her throughout the game.
This scene shows a leaf falling into her hair, suggesting that this is now fall. The player may
assume that the previous interactions may have been during spring or summer, but there is no
indication that much time has passed as the young women never changes physically. This
moment is also the first foreshadowing that the young woman is ill as she coughs and then
slowly struggles to keep her eyes open. The bench disappears and is replaced with a hospital bed.
The affordance of the game medium here is the shifting of the backgrounds and character
depiction to both show changes of time, and in the case of the young woman, changes in health.
As there is no dialogue, indication of time from a clock face or calendar, the player has to make
these connections. Millard argues that one of the core elements of hypertextuality games possess
is “in the way they manage structure and how that structure impacts the reader/player” (Millard
126). Thus far, the player may assume that these moments are in sequential order based on the
information provided, but it is possible that this is not the case and that these scenes are out of
chronological order or that other orders could be effective in telling the narrative. While this
game does not provide variations in terms of decisions or pathways, by viewing the information in different ways, the player still has a large amount of control over aspects of the narrative.

Once the young woman becomes ill, the game play becomes focused on her face, revealing it from leaves or putting it back together from squiggled lines, while discordant violins play with loud tics from a clock, which reveal the main character’s emotional anguish as she becomes more ill. The ticking of the clock can also signify the fact that she is dying, and the main character is frantically trying to “fix” her, but is unable to do so. Towards the end of the hospital scene, her face is missing entirely and is replaced by a large yellow question mark and a single floating square that has a flower pattern appears. As the scene progresses, it is shown that the square is actually her heart monitor, and the rest of the hospital room comes in and out of focus. The room disappears so that the young woman is shown sitting on a bench in space, suggesting that she has passed away as the monitor turns bright red. The discordant violins smooth out to the game’s theme music and the clock continues to tick, until the monitor turns red and then the clicking is replaced by a single tone showing a flatline heartbeat. As the next scene focuses on a headstone, it can be inferred that the young woman has died from her unnamed illness. When the final image of the young woman is shown in the credit’s scene, it is in the form of the photograph that was previously blacked out in the introduction, suggesting that the memory has been restored after revisiting his past through his dreams. The image shows the main character as a young man beside the young woman, who is giving him bunny ears in the photo, and their dog. Everyone looks happy and the background is the same bright yellow as the butterfly. This image is particularly important because it explains why the main character ages, but the woman always appears the same way.
The only other characters that are shown in much detail in Alzheimer’s Memories are the three musicians, but the player must also actively make connections with the gameplay to understand their relationship. As with the young woman, none of these characters are named nor are there any indications of time passing except for one clear sunset. When the player initially interacts with the musicians with their instruments, they don’t have any dialogue, but make annoyed noises. It is only after the player starts to repeat their songs by clicking on different colored notes in the correct order do they stop making these sounds. The scene is directly after the music minigame and these characters are clearly friends now seen in their laughter and sharing drinks on the beach. Like the scene where the young woman is shown in an Art Nouveau style, this scene also has warmer colors, even though their faces never gain the same level of detail as her face does. These scenes show the development of the relationship between these characters, but with less cues on the time spent together and it is also unclear if they continued to meet after the main character meets the young woman.

Another unclear element is the reasoning behind the minigame as the main character is never shown with instruments and it is unclear if they played or just enjoyed the musician’s music. This scene can viewed as just a means of engagement in the narrative or as a way to incorporate music into the narrative, but who these characters are and why they are never shown again after this scene is never explained. Though the player only follows the main character’s experiences, these moments with the young woman and the musicians does create multiple narratives within the text that also serve the emphases the fragmentary nature of AD. As Landow argues that hypertext disrupts a cohesive timeline, this game also prevents the player from forming a non-distributable timeframe. Ensslin argues that these open ended or unfinished
narratives force the reader to engage in play at both the narrative and gameplay level (62). This lack of information leaves a large gap in the narrative that the player does not have enough information to fully explain. It is possible that there is no more information to reflect the main character’s memory deterioration or as a shift in the main character’s dreams that leave this particular story unfinished. In the final part to this scene, the musicians are suddenly far away from the main character and have very vague shapes. While one waves his hand in either greeting or farewell, they fade as the main character blinks. These blinks have been used as a time transition as well, so it is unclear if the dream is shifting to the next memory or if this is the last memory he has of them. This fading could also represent the deaths of the neurons which results in memory loss, so there are no memories of them because his AD has damaged or destroyed the area of the brain that housed them.

**Environment In Alzheimer’s Memories**

While the environment has been described briefly in the discussion of the characters, these three scenes of the garden, the cemetery, and the city showcase the medium of games to add information and set the tone, both of which are particularly important to this game as there is no narration or printed text beyond the beginning and ending of the game. These environmental details also contribute to the mix of abstract and realism that Yue was describing about dreams. While the garden scene creates a sense of reality, the headstone scene clearly mixes in the main character’s feelings, and the city is a mix of both. The variety of these scenes show how games can utilize environmental details to set the tone for a game.
The environment of the garden is unique in the game in terms size and color. While previous scenes kept the player focused on one particular environment, the minigame of hide and seek, has the player moving around different aspects of the garden, providing a more concrete example of environment compared to other more abstract scenes. As the player searches for the young woman, they are able to relive this memory alongside the main character rather than simply observe or just randomly clicking on objects. Compared to other interactive scenes, this one is the most concrete and clearly linked to the narrative as a date with the young woman.

There is also unique depth perception as the flowers are close to the front of the image and slightly out of focus make it feel like the player is seeing out the main character’s eyes more distinctly compared to other scenes. This scene also changes based on the player’s interaction with the flowers, causing them to gain color and spin around, making the environment slightly more realistic by adding colors to flowers, rather than keeping everything in black and white outlines. At the same time, the animation provides slight movement to the screen and keeps the abstract feeling of the dream. This realism can also be related to the happiness of the mood depicted through the bright colors, the upbeat jazz music, and gameplay, compared to the other scenes discussed here.

Unlike the happiness in the garden scene, the headstone scene utilizes darkness and light as well as ambiance to indicate the main character’s feelings. The headstone scene begins in a storm and with a completely darkened screen that players have to interact with to gain glimpses of objects and determine where they are, a direct shift from the previous scene at the young woman’s hospital bed. There is a loud roaring wind and no music in the initial part of this scene. The only clear objects here are the sad dog with its head bowed and the headstone which is
scribbled out in thick black marks. This scribble can represent the main character’s feelings about the headstone; they can’t even think about it, but they also can’t deny it is there. As the player continues to click on the various leaves strewn on the ground or in the air, the colors slowly come back, and the loud wind starts to die down as well. While the wind never fully stops, it becomes quieter and less oppressive. The scene lights up to become a field with the grave no longer scribbled out. While the headstone is now fully revealed, there are no names or dates inscribed, so there is no more information provided on the young woman. The main character leaves flowers and the camera pans upwards following some petals from the flowers going up to the blue sky. The sky is also depicted in a distinctly different style from the rest of the hand drawn characters and environment as it looks like a picture of the actual sky. This division makes it stand out more, adding a mix of drawn and realistic elements that makes this scene otherworldly. Through the medium of the game, the passage of time and acceptance of the young woman’s death can be shown through the changes in the environment rather than relying on dialogue.

The final environment, the city is one of the most jarring transitions in the game and helps represent the confusion and disorientation of AD. The initial shots of the city show the large vaguely shaped structures looming over the main character. The bright neon-colored lights flash on and off, but there are no text or real landmarks to clarify where the main character is in this place. When the camera switches to a street view, there are even fewer cues such as a blank street sign and blocked areas of color flash and don’t give any indication where the main character is and what they are doing there. While there are other people moving around the city, their forms are unclear and are just a general outline. The introduction to the city had a long
black screen pause before it started, so there is no introduction to why the character is suddenly here. Millard notes how transitions in hybrid game/hypertext works, which he terms Strange Hypertext, can utilize hypertextual elements to impact their narratives such the way the text fragments and falls apart in Alan Trotter’s game *All This Rotting* (129). Trotter’s game utilizes unstable text to express memory loss, but while *Alzheimer’s Memories* does not use text, it does have a similar impact with these transitions between scenes. Without any linear narrative or connecting information, the main character’s fragmented memories and sense of selfhood require the player to active re-construct these memories as best as possible to create the narrative. This transition in particular is difficult as the style is completely different from previous scenes and also does not directly relate to the narrative of the musicians or the young woman. Eventually, there is the final white screen with dialogue as an unnamed person approaches the main character. The player never hears or reads the main character’s responses and it is clear that he initially tries to get away from this person as they ask where he is going after they offer to help. It is suggested that a police officer or someone similar helps him get home and asks that he not “wander off” again. Noelannah *et al.* found that 3 out of 5 AD patients are prone to wandering, a dangerous habit of leaving their homes or facilities and going into an unfamiliar place, often with no memory of how they got there (615). The medium of the game shows how disruptive and jarring the lack of memory would be in this situation along with the embarrassment of not being able to find your way back home.

While *Alzheimer’s Memories* does not provide much dialogue, the player is able to pull these dream sequences together to form a narrative of the main character’s life. Despite never being named, the main character’s story is clearly depicted through these scenes and this game
Before I Forget Summary

*Before I Forget* by 3-Fold Games provides the most information about living with AD out of the three games described here. Taking about an hour to complete, the fictional narrative follows Dr. Sunita Appleby as she wakes up and moves around her house looking for her husband, a famous pianist named Dylan Appleby. As with the other three games, the gameplay focuses on interacting with different objects and the player must connect Sunita’s dialogue to the objects to complete the narrative. While this game focuses more on progression through discovery compared to the other two games, there are still some scenes that utilize progression through scripted scenarios such as the memory scenes and ending (Carstensdottir et al. 4). *Before I Forget* uses similar gameplay to *Forget Me Knot* as interacting with various objects prompts Sunita to respond to the item and, like Harold, Sunita is unaware that she has AD. This game is somewhat similar to *Alzheimer’s Memories* in that the player is entering into Sunita’s memories,
but *Before I Forget* does provide dialogue both within the memory and often afterwards, making it easier for the player to make the connections to the events and their significance in Sunita’s life. Also similarly to *Alzheimer’s Memories*, the environment becomes more colorful as the player interacts with the various objects in the houses. While the game takes place within Sunita’s house, through her memories, the player is able to visit different areas and time periods.

The strength of this particular game is its incorporation of AD symptoms within the gameplay and narrative itself. While all three games emphasize memory loss, due to the length and gameplay, the player is able to gain a greater understanding of the disease. While some games use what is commonly referred to as invisible walls that prevent a player from entering an area outside of the game or limiting how far the player can go into an environment, *Before I Forget* uses the concept of voids, a visual delusion that some AD patients struggle with as they imagine a large hole in the ground that doesn’t actually exist. The game also shows how disorienting even familiar layouts can be as Sunita attempts to find the bathroom, but keeps looping back into a closet no matter what door the player uses. These elements add another layer of depth to the game and connect it more clearly to AD compared to the other games.

**Selfhood In Before I Forget**

Similarly to *Forget Me Knot*, the player learns the name and background information of the main character by interacting with items in the environment, but *Before I Forget* utilizes color with interaction in a similar way to *Alzheimer’s Memories*. Through this combination of information hunting and environmental change, the player is able to gain information on Sunita throughout the narrative. Sunita won several awards for her scientific achievement seen in the
trophy of a planet. The plaque reads “Scientific Discovery of the Year 1975 Dr. Sunita Appleby.” While Sunita acknowledges that this is her name and that the award is “impressive” she doesn’t think that it can be her. Initially, the player may be confused by this comment as Sunita interacts with a magazine that initially appears blank until the player interacts with it. Once the player has clicked on it, Sunita’s face appears on the cover. Again, Sunita acknowledges that this is her, but misunderstands the subheading of “boldly going where no woman has gone before” as suggesting that she needs to go somewhere. The thought of leaving makes her anxious and she repeats that she’s not going anywhere.

Viewing Sunita’s sense of selfhood through the metaphor of a kaleidoscope continues to complicate her concept of selfhood. For Sunita, interacting with the various objects are means of remembering significant moments in her life. These objects not only reveal more information on Sunita’s past, but also provide more details about important people in her life and provide a means for the player to learn that she has AD. The objects themselves may be viewed as the different colors of the kaleidoscope, but Before I Forget goes a step further and allows Sunita to become these past versions of herself. Similarly to Alzheimer’s Memories, when Sunita enters these memories, her current self fades back as the world becomes washed in watercolors and she re-enters the moment of her memory. Unlike Alzheimer’s Memories, Before I Forget relies heavily on dialogue and printed text on the objects to provide context for the memories. Sunita further fragments herself in her reactions to these memories or objects as she sometimes is able to remember the events, but is also often confused by the information she sees. This creates a dual narrative in what the player is aware of and what Sunita is able to remember. Austin argues that the players in Hellblade must become accustomed to Senua’s perspective and the actual
events at the same time and players of Before I Forget must do something similar. Clicking on different objects will sometimes only provoke some dialogue and added colors to the area, while others will cause Sunita to fall into a memory before returning back to the room. While there are time cues and changes in the environment to indicate shifts, the reality of Sunita’s memories are just as vivid, in some cases even more so, than the actual events, interrupting the linearity of the game narrative.

The player must continue to interact with the objects in the environment to gain additional information on Sunita. While Alzheimer’s Memories added color and animation to the area, by clicking on different objects, in Before I Forget faces and words are added alongside the color. As the player moves around the room, they are able to gain more information on Sunita’s career. The magazine describes her as an Indian Cosmologist and there are books and models related to space all around the room. Sunita never admits that she has AD until the very end of the game; however, there are hints that something is wrong as there is a note beside the trophy stating to stop moving the trophy to different places. As both Sunita and her carer Maria leave notes, it is unclear who wrote this note. It is also important to note that even if the player interacts with everything possible within the room, the color on the walls and objects is always incomplete, suggesting that something is still missing and the player is not able to fully restore it, no matter what they interact with or if they revisit the room multiple times during the game. This applies to Ensslin’s argument about open endings as there will be pieces of information that are never provided within the work, but this allows that players can fill these gaps themselves, making the experience unique and more playful (62). For example, the gaps in color suggest that
while Sunita can use memory cues and may remember some aspects of these memories, AD has damaged her brain, so she will never have full function again.

While some of the memories are prompted just by clicking on an object, the player often has to engage with the objects for a longer period of time to gain more information and some of this information is shared by both the player and Sunita, but some is only understood or retained by the player. For example, interacting with Sunita’s computer shows a collection of emails that are over six years old. While one is from Dylan, showing that he was on tour in America when Sunita’s memory problems began interrupting her life, the rest of the emails focus on her work. The player can read through these emails to see that Klass Vandemeer called Sunita’s conference a “disaster” and asks for a meeting and that Sunita’s friend, Desdemona Archer, reached out to her after she announced that she was going to retire, but the large gap between emails and Archer’s apology for the delay suggests that they grew apart after Sunita’s diagnosis. Sunita does not respond to Archer’s email, but instead is confused by Vandemeer’s response and complains that he often made things difficult. The player can also interact with a letter in the desk drawer from Desmond Powell that acknowledges Sunita’s retirement and wishes her well “managing” her “condition.” Sunita denies knowing anything about the condition he is referring to and says that she will call him to correct this mistake. Alzheimer’s Disease is never mentioned by Sunita and she does not always acknowledge that the player has interacted with something, so it falls largely to the player to make connections between the objects and the narrative as they cannot rely on Sunita to do so.

Despite reading emails and seeing medication in her bathroom, Sunita is unable to fully acknowledge that she has AD, forcing the reader to put this information together themselves and
have it confirmed, rather than being told by the narrative. By entering her bathroom, the player can find a daily medicine container and when the player interacts with it, the words “S Appleby—Donepezil One tablet to be taken once a day after food” appear. Sunita is hesitant to take the medication because she does not feel sick and leaves the bathroom without taking any medication. Some of the daily containers are open, suggesting that she has taken some medication, but this either happened before the beginning of the game or Sunita has forgotten, as the player never has an option to have Sunita take the medication. It is also important to note that this is the same drug taken by Harold in *Forget Me Knot* and is intended to treat early to mild AD symptoms. Unlike in *Forget Me Knot*, there is no way for the player to understand what the medication is for as there is no description or medical book that provides this information within the game. This may suggest that the developers have an assumed audience that is familiar with this medication. If the player wants to learn more about this medication, they would have to look up this information outside of the gameplay. While this may encourage players to do a little research into what this medication is for and what it treats, it is also possible that players will not be able to connect this medication to AD at all without any additional information.

**Social Connections In Before I Forget**

While the only character that the player directly interacts with is Sunita, through the memories and notes around the apartment, the player also interacts with three key characters that help build Sunita’s history and add more detail to her character: her husband Dylan, her Leela Auntie, and her carer Maria. While Maria is the only character who is alive and present during the timeline of the game, she is actually the least connected to Sunita as they met after her
diagnosis. This stark difference between how Sunita treats the living and dead characters makes the memories seem more real than the actual events of the game. The art style of these characters and their interactions with Sunita show the one benefit to having AD; through these memories and flashbacks, these characters are alive again. This game argues against Aarseth’s argument that single-person games cannot address interpersonal relationships as much of Sunita’s selfhood and understanding of her past comes through her relationships with others. The player must interact with the various objects within the apartment to begin the minigame or scripted scene, but the player must also combine the information gained from these interactions with what they have already learned through the gameplay as Sunita does not always remember or becomes confused, adding to the player’s interactivity and gap-filling. Meakin, Vaughan, and Cullen argue that these interactions with the objects, scripted scenes, and gap-filling all emphasize the critical role of narrative. This narrative can only be built through the memories of these other characters, as Sunita is unable to relay this information on her own without prompting from the objects.

Dylan, Sunita’s husband, is referenced right at the start of the gameplay and the goal, initially at least, seems to be to find where Dylan has gone. However, as the player continues to investigate the apartment, there are several hints that Sunita is the only one staying there. In her bedroom, only one side of the bed shows that someone has slept in it and at the bedside table is a note reading “I love you,” but Sunita notes that he, meaning Dylan, has forgotten the heart. This missing drawing suggests that Dylan may not have been the one who wrote it. Despite going through the apartment and not finding Dylan, Sunita still calls for him and leaves out a place setting for him at dinner. While Sunita keeps expecting to find Dylan around the corner of the
next room, the player can slowly infer that Dylan is deceased. As with Sunita’s past, the player gains information on Dylan by interacting with various objects and Sunita comments on many of them such as the pamphlet. The pamphlet shows a man smoking a cigarette in front of a picture of a city. The title reads “Live in Concert Dylan Appleby plays his Bach Goldberg variations Amsterdam concert.” While there is no piano on the cover, the player learns that he was a pianist later in the game and Sunita comments on hearing him play several times. Though Sunita may not comment on all of the objects, there are several cues that she struggles understanding some concepts. For example, when she finds a single wedding ring and Dylan’s pocket watch in a drawer. The player can understand that these personal objects mean that Dylan has died, but Sunita can only comment that she has a matching ring, and she also struggles to name the pocket watch correctly. These references create another break between Sunita’s understanding and the player’s understanding of the past.

Sunita’s past and connections to Dylan are not only provided in these interactions and scripted scenes, but also in how the narrative ties the game’s music back to Dylan. While all three of these games have some form of music and sound effects, *Before I Forget* connects the piano playing to Dylan’s last song, “A Song for Sunita,” that he was writing for her before he died. This is the song that plays in the background of the game and typically only starts when Sunita is thinking about Dylan; otherwise, there are some sounds like clock ticking, but nothing as significant as the piano music. Sunita actually connects hearing this music to Dylan still being in the apartment as shown in the dialogue, “I can hear you playing…where are you?” and later, even after reading the announcement of Dylan’s accident and death in the newspaper, she states, “No…no you can’t be. I can still hear you playing.” As previously mentioned, Ryan argued that
music can enhance emotion; however, Before I Forget utilizes AD symptoms with the incorporation of music. Patients with AD can have auditory hallucinations and hallucinations are one of the most common symptoms of AD (El Haj et al. 713). It is also important to note that hallucinations are more common as the disease progresses, so the increase of hallucinations seen in the gameplay may also link to Sunita’s worsening symptoms (El Haj et al. 715). As the music was usually tied to Dylan, it is possible that Sunita was hearing his playing because she connected him to piano music, so she heard it when she thought of him. Before I Forget utilizes a common symptom in AD patient as part of the game’s mechanics while also providing another emotional link between Sunita and Dylan.

Another personal connection to Sunita that can only be found through memories is her relationship to Leela Auntie. This particular memory has a different transition from all the other memories, suggesting that this memory is older than the others as Sunita sounds like a child in these scenes. In Indian culture, referring to another person as Auntie is a sign of respect to another older woman, and it is never clear if there is any actual blood relationship between these two characters. There are two minigames associated with Leela Auntie’s memories. For both memories, Sunita either looks down through a telescope that becomes a tunnel or looks into her empty teacup which also becomes a tunnel. This also suggests that these memories are much older as the other memories are tied directly to the apartment itself, while these memories take place in India. While there are minigames featuring Dylan identifying stars with Sunita’s help, these show Sunita learning not only the stars, but cultural myths and legends associated with them. Despite Sunita’s difficulty in retaining new memories, such as her relationship with her carer Maria, this memory is detailed and clear, showing how AD can directly prevent short term
memories from being processed into long term memories, but some memories remain intact. While Leela Auntie is never directly present the game, through these minigames, the player is able to learn about her and understand her importance to Sunita, pushing back against Aarseth’s argument that games can only focus on the self. Through these interactive memories, *Before I Forget* is able to provide these social connections both to Sunita’s friends and family, but also to her culture. Though this game focuses on the player collected these fragmented memories to understand Sunita’s selfhood, these social connections hold as much as weight, if not more so, as the actual events in her flat. These moments of fantasy allow both an escape from the symptoms of AD, while also illuminating on the impacts of AD on the family and providing an insight into the main character.

Unlike the memories which have a more dreamlike quality, the final social connection that Sunita has is to her carer Maria is grounded in the current events of the game. While this is the most recent connection, it the least interactive. As with the emails, letters, and newspapers scattered around the house, the only connection the player has to Maria is through notes in the kitchen and a voice message left on the answering machine. Similarly to Izzie’s calls and messages to Harold in *Forget Me Knot*, these messages provide some insight into Sunita’s daily memory struggles. The note reads “SUNITA. DO NOT USE THE STOVE!! YOUR LUNCH IS IN THE FRIDGE. — Maria.” The use of all capital letters with two underline marks under not, show Maria’s frustration with Sunita’s attempts to cook, likely due to a safety hazard as Sunita may forget that something is cooking and set something on fire. Sunita gets angry at the note saying, “I shall use the stove if I want to! Who is Maria?” obviously not understanding the danger or remembering that Maria is her carer. The other notes on the counter and on the fridge
provide more clues to Sunita’s memory loss. The notes state that the ham is no longer safe to eat, but Sunita claims she just bought it. The cabinets are also filled with canned peaches and a note from Maria states to stop buying peaches, while a note, likely written by Sunita, states to buy more peaches. Dylan would eat peaches regularly, so Sunita was buying them with the assumption that Dylan would eat them, but as he is dead, canned peaches fill the cabinets. When Sunita hears the voice message, she is scared of Maria coming and isn’t able to remember her at all. The only reason she doesn’t run from the apartment in fear is that she wants to wait for Dylan before she leaves. Again, this widens the divide between what Sunita knows and understands compared to what the player is privy to and the player can make these connections between characters that Sunita is unable to retain.

**Environment In Before I Forget**

The environment in *Before I Forget* provides information on Sunita’s state of mind to the reader such as when she is in a flashback, when she is confused, or when she is hallucinating. To indicate that the player, and Sunita, are experiencing a flashback, the environment of the game changes by having color rain down from the top of the screen, smoothly transitioning into another environment. In the first of these moments, the memory shows a part of the first time Dylan and Sunita met. It is also important to note that Sunita’s text is white during the present game time and is gold when in a memory, suggesting that she has been washed out due to her illness, but is more complete during the memory. Dylan’s voice is always in a different font and in blue text and Leela Auntie’s is in a similar font to Sunita’s and in orange. While these characters are never shown on screen, these different text colors and styles do provide them a
small means of characterization. These transitions happen often in the game and are scripted moments that are prompted by interacting with an object that causes Sunita to go into a specific memory. The memory is prompted by touching an umbrella which relates back to when Dylan shared his umbrella with Sunita when they first met during a rainstorm in Amsterdam. While these memories are often detailed, only the memories with Leela Auntie have full bright color, the rest are slightly washed out and hazy. As previously discussed, while the initial environment appears washed out, by interacting with the objects in the rooms, the player is able to make changes in the environment and add more detail. There are clear details in the memory, but they are difficult to make out, which also creates a sharp contrast to the present moment’s environment which is much more detailed.

However, while the present moment’s environment tends to be more detailed, there are several instances where the environment will suddenly be darker and have fog, showing a physical representation of Sunita’s confusion and disorientation. Austin points out that the goal of *Hellblade* is to overcome the “darkness” that represents Senua’s psychosis, which raises concerns about how games may add to the stigmatization for people with mental health conditions or disorders. In *Before I Forget*, the negative side effects of AD are not something to be overcome, but part of Sunita’s experience as a person with AD. After exploring the apartment for the first time, the narrative is interrupted by Sunita needing the bathroom, but whenever the player clicks on a door, they will open the closet door, regardless of which door they try. This looping process shows how disorienting even a small and familiar space can be to AD patients. According to the *Alzheimer’s Society*’s article “Changes of Behavior,” being restless or repeating actions is a sign of distress for AD patients and can be a sign that they need to use the restroom.
as Sunita does in this scene. Sunita is aware that this is a problem and shows her frustration in the dialogue, “Was it this way? They look the same. I can’t… how silly!” Though the player can try to navigate to the bathroom, just as the door opens, Sunita soils herself and is embarrassed. This scene is particularly important as it occurs after the flashback, which Sunita enjoyed reliving the moment. This juxtaposition shows the negative side effects of AD and how it can be incredibly frustrating and humiliating to be unable to control bodily functions or navigate even a small space. Through the medium of the game, the player is able to experience a simulation of the lovely flashbacks alongside the reality of living with AD.

As previously mentioned, Before I Forget uses the hallucination of voids to create barriers, showing how a game mechanic can pull from a specific diagnosis. Studies have shown that some AD patients view patterns or colors on rugs as a hole or void that they are unable to cross (Noelannah et al.). These patterns are used by some care facilities to prevent AD patients from leaving without the staff knowing (Noelannah et al. and Hewawasam). Rather than using an invisible wall or barrier to prevent the player from entering an area before the correct moment, using voids again represents the experiences as an AD patient to the player. One problem with these voids is the fact that they are never explained and the player may not understand why Sunita is seeing a random hole in the ground. This scene is similar to the lack of information with the presentation of Sunita’s medication and again assumes that the audience is familiar with AD. However, while there may be a gap between player understanding, using actual symptoms as part of the game mechanics shows the flexibility and creativity of the medium of games to represent brain illnesses.
Before I Forget provides an example of how the medium of games can incorporate symptoms of a condition into the gameplay, without detracting from the narrative. Through the use of auditory and visual hallucinations, memory loss, confusion, and issues with independence, this game provides a unique insight into living with AD through beautiful imagery and music. Unlike Forget Me Knot, there is limited information about AD within the game itself, which implies the developers assumed their players would have some knowledge of AD. This can be problematic as Sunita is only able to acknowledge her AD at the end of the game, so players may not understand some of her reactions that relate to her AD. While the ending may be considered depressing, if the player assumes that Sunita has passed, it also represents the reality of the diagnosis of AD and Sunita is at peace, seen in her reunion with Dylan. Though this game has one of the longest playthroughs which may discourage some players, Before I Forget shows the benefits of consulting with researchers during the development of the game and how this research can be incorporated into the narrative and the gameplay.

Conclusion

Neurogames provide unique interactive representations of AD that challenge the concept of fragmentation in AD and also show the wider impact of AD beyond the patient. They can be made with the aid of neurological research to promote awareness and educate the player such as Forget Me Knot and Before I Forget and allow the players to explore the simulation of AD or other neurological condition in a non-threatening and narrative driven game. Games like Forget Me Knot, shows how much detail and narrative can be created in such a short span of time and requires detailed user interaction to complete the narrative. Through the medium of games,
*Forget Me Knot* is able to introduce multiple characters and provide snippets of Harold’s past and current experiences within a twenty-minute playtime. This game provides information on AD medication and reveals the difficulties and shifting levels of independence as the disease progresses. *Before I Forget* takes advantage of a longer playtime by creating several detailed memories that cultivate a mystery romance game and incorporates symptoms of AD such as visual and auditory hallucinations into the gameplay itself.

Neurogames may not use research to guide their narrative or determine their gameplay, but instead, they can be made to explore human experiences and memory such as *Alzheimer’s Memories*. Through abstract patterns and designs, *Alzheimer’s Memories* utilizes the concept of dreams to provide a wide range of memories and interactions for the player to create a sense of the main character’s past and more recent events in their life. This particular game emphasizes the ability of the player to become involved in the creation of the narrative as the lack of dialogue and text, save at the beginning of the game, requires the player to build the narrative themselves. Viewing these games through the medium of hypertext emphasizes the gap-filling that the player must participate in to understand the narrative of the game and to gain an understanding of the main characters and their relationships. All of these games focus on the main character’s life and memories rather than just their illness, which supports their selfhood and presents themselves as a whole rather than narrowing them to victims of an illness.

It is important to note that while *Forget Me Knot* and *Before I Forget* directly state that they utilized neuroscience for their production, these neurogames are not Serious Games. Rather than disregarding these games as only problematic, these neurogames are focused on entertainment rather than education, still allow researchers to view these kinds of games as a
means of identifying stereotypes that are being continued and this may inform public outreach and educational goals. Applying Ensslin’s and Ryan’s approaches towards narrative in games to these neurogames, also provides the player with a level of separation of the game, as they are aware of the game medium and may question their own preconceptions while they play. Though stereotypes of mental illness, especially those presented in horror video games, is problematic, more positive and realistic depictions of mental illness does exist in games and players are interested in exploring them.

Using digital mediums to recreate or explore the human thought process is not a new concept and several researchers such as Jay David Bolter in *Writing Space* have argued that hypertext may be a way of recreating the process of human thought (42). Rettberg made a similar claim arguing that, “works of electronic literature present us with crafted experiences that reflect changes wrought by the digital turn taking place in the nature of communication, textuality, society, and perhaps even the structure of human thought” (Rettberg 18). A key concern with this line of argument is the fact that no scientists have been able to represent or recreate the process in which our neurons form, pull, and create new memories. As Joseph Tabbi argues in *Cognitive Fictions*, we may be able to observe fragments of this process, but we cannot currently represent the entire process of human thought, so re-creating it through digital means is not realistic (Tabbi xxi). While these neurogames are not presenting the direct connections between synapses, these games present representations of living with a neurodegenerative condition that may complicate preconceived ideas and stereotypes about AD. *Forget Me Knot* and *Before I Forget* show the impact of physical objects on memory, even if there are still gaps in the recollection and *Alzheimer's Memories* emphasizes a similar connection, only utilizing the connections between
people rather than objects. Though we don’t have games or simulations that can properly express the structure of human thought or precisely express unique cognitive experiences, neurogames offer opportunities to explore different representations of cognition. While these hypertextual elements are inherent within these neurogames, the following chapters will focus on print neuronarratives and how their use of hypertextual elements complicates their representations of Alzheimer’s Disease.
CHAPTER 2: DRAW MY LIFE: ALZHEIMER DISEASE NEUROCOMICS

Introduction

Comics have been used as a medium for describing a person’s medical conditions or illnesses for decades. Justin Green’s work *Binky Brown Meets the Holy Virgin Mary* (1972) was the first autobiographical comic and one that focused on the author’s obsessive compulsive disorder (OCD) (Chute 240). Other more recent famous works have followed such as David B.’s *Epileptic* (2006), Allie Borsh’s *Hyperbole and a Half* (2009), and Ellen Forney’s *Marbles* (2012). Comics that focus on health conditions or illnesses are often defined as graphic medicine. Graphic medicine combines narrative with images to better express a person’s experience with an illness or condition or to illustrate how a medical procedure or treatment works. While graphic medicine can be just an illustrated explanation, Czerwiec *et al.* argues in *Graphic Medicine Manifesto* that they can provide much more than that as “graphic medicine is also a movement for change that challenges the dominant methods of scholarship in healthcare, offering a more inclusive perspective of medicine, illness, disability, caregiving and being cared for” (Czerwiec *et al.* 2). Graphic medicine allows patients or carers to express their experiences in a flexible genre. As comics have been “associated with cultural change” it makes comics “ideal for exploring taboo or forbidden areas of illness and healthcare” allowing for more flexibility in form as well as in content (Czerweic *et al.* 3). In the introduction to *Graphic Reproduction*, Johnson argues that, “Scholars and practitioners of graphic medicine explore how comics can effectively represent the many voices and bodies involved in any healthcare encounter and they draw on this multiplicity in productive and unexpected ways” (Johnson
“Introduction” 4). These comics allow multiple voices an opportunity to discuss a topic that would otherwise be considered taboo (Johnson “Introduction” 4). A similar argument can be made for graphic works that focus on Alzheimer’s Disease (AD). As AD is a terminal illness that is associated with loss of selfhood and loss of dignity, the stigmas surrounding the disease often prevent conversations about the disease, which in turn continue to perpetuate the stereotypes surrounding AD.

**Neurocomics**

This chapter will focus on neurocomics, or comics that focus on the brain, brain illness, or cognition at the core of the narrative. While it can be debated if neurocomics are a genre by themselves or if they are a sub-genre of graphic medicine, these comics serve as a means of expression for topics that are deeply personal and individualistic, as everyone has a unique cognitive experience of the world. These works utilize personal narrative to give an account of their external and internal experiences. In the chapter, “Neurocomics and Neuroimaging,” Tougaw argues that for neurocomics, “the juxtaposition of words and images reminds readers that representation is never transparent. Words and images translate or distort experience” (Tougaw 205). Tougaw claims that visual methods of understanding the brain, such as PET and MRI scans, lack the personal connection to the patient themselves. He points out that while brain scans seek to showcase the physical brain and its activities, it does not speak to personhood which is what neurocomics are able to focus on, fulfilling the epistemological gaps left by just using the sciences (Tougaw 226). Neurocomics are able to utilize a mix of media to produce meanings. Tougaw points out that these neurocomics are representations of the brain showing
that a brain simply isn’t “found” it is “made” (226). AD patients must re-evaluate their concept of selfhood and their relationships to others after their diagnosis. As they begin to lose their memories, many feel that their sense of self has become fragmented and they create multiple versions of themselves, both before their diagnosis, but also during the various stages of AD. AD patients’ cognitive experience has been significantly changed by their illness and this change also directly impacts their friends and family members significantly, making AD neurocomics a unique exploration of selfhood and social connections.

While this area of study is particularly rich and there are many other neurocomics to explore, the scope of this chapter will argue that reading neurocomics through the lens of hypertext complicates stereotypical images of AD and the concept of fragmentation of selfhood. In *Understanding Comics*, Scott McCloud argues that that readers of comics require closure and the active process of filling in the gaps between panels, images, and pages are all in order to attain closure (63-64). Charles Hatfield in *Alternative Comics* supports McCloud’s claim and describes the process of gap filling as a “translation,” though he also acknowledges that this process can be difficult when the images and text seem disjointed (41-43). When reading these neurocomics through the lens of hypertext, this desire for closure becomes more complicated due to the progressive nature of the patients’ illness. Jay Bolter in *Writing Space* argues that hypertext works “threaten to never be resolved,” so viewing these works through the lens of hypertexts shows the dynamic between the reader searching for closure and the neurocomic not always providing it (130). Reading hypertextual works forces the reader to view the medium as a whole and acknowledge the non-linear narration, despite the reader’s desire for linear narrative (Bolter 137). The AD patient is losing their memories and their sense of time, thus creating
multiple versions of the same character as the character imagines themselves in different time periods and in different states of cognition. To further complicate this fragmentation, the AD patient is sometimes aware that they have lost some aspect of themselves and may have moments of clarity, so even the process of fragmentation is not consistent. Through this creation of multiple selves, the linear narrative becomes more complicated, and this fragmentation of selfhood creates sections of the comic that exist outside of any clear temporal relationship to the narrative. These neurocomics disrupt attempts of closure, requiring the reader to actively engage with the comic at the text, image, and page level to move forward with the narrative, and in doing so, complicate the linear progression of AD and challenge the concept of total loss of selfhood.

As McCloud notes, reading comics is an active process and the gutter is like a limbo requiring that reads take “two separate images and transform them into a single idea” (66). By reading these works through the lens of hypertext, the reader not only fills in the gaps between pages and the gutter, but also must connect the images and text together and follow the ever-changing sense of time and shift in memory from the AD patients. Bolter argues that hypertext requires gap-filling as well, even if the author has selected the text and images, the reader must pull them together to make sense of the narrative (173). Applying the lens of hypertext to these works are appropriate as Landow argues in Hypertext 3.0 that hypertext can be used, “as a lens, or new agent of perception, to reveal something previously unnoticed or unnoticeable, and it then extrapolates the results of this inquiry to predict future developments” (219). As AD results in the fragmentation of the person’s memory, reading these comics through the lens of hypertext not only allows the reader to see the progression of the illness, but also the connections between
the present narrative, the person’s past, and how their memories are preserved through their relationships as the reader actively engages in gap filling between the image and text and the past and present.

This chapter will examine three neurocomics: *Wrinkles* by Paco Roca, *Tangles* by Sarah Leavitt, and *Aliceheimer’s* by Dana Walrath. These neurocomics focus on patients with AD and utilize the medium of comics and graphic works to complicate the concept of selfhood and provide unique representations of AD. They were chosen for this chapter due to their non-linearity and structure, which complicates the stereotypical linear progression of an AD patient towards the end of their life, representations of AD patients, and their exploration of social and carer relationships. *Wrinkles*, though initially focused on Emilio’s AD, shifts to focus on the developing relationship with his friend and caregiver Miguel, rather than emphasizing Emilio’s loss of awareness. *Tangles* relates the entire process of Leavitt’s mother Midge’s progression with AD, but while Midge’s loss of cognition remains a key feature of the comic, Midge and Leavitt both become represented in series of multiple selves that intersect with each other, even after Midge’s passing. Finally, *Aliceheimer’s* images use cut of pieces of *Alice in Wonderland* text to re-create a version of her mother, embracing her AD as a magical power rather than a progressive neurological disease.

Similarly to the neurogames discussed in Chapter 1, neurocomics are more likely written by carers, rather than the AD patient themselves due to the process of creating the medium, but this genre allows a space for carers to express their experiences with AD. These neurocomics transform the AD patient into multiple selves and intertwine these selves with narratives of others, in particular their carers, but also with the other characters in the stories. Through the
comic medium, the environments also provide a means of expressing the characters’ mental state and provide another layer that the readers must actively engage with to follow the narrative. These three works create a dual narrative of the AD patient and their carer, explore the social interactions between characters, and utilize the environment to provide details that are not included within the limited dialogue.

Wrinkles Summary

The first work in this collection is the only one that is not an autobiographical account of a carer for an AD relative, but Wrinkles remains one of the most well-known comics on AD through its focus on the relationship between AD patient and carer. Wrinkles [Spanish title Arrugas] was published in 2007 and translated into English in 2016. It was also adapted into an animated film in 2011. It has won multiple awards in many countries, including best work by a Spanish author (Fraser 137). Wrinkles shows how one of the main characters, Emilio, is struggling with the early stages AD. His family is frustrated with his condition and feels that they are unable to care for him, so they choose to send him to a nursing home. The rest of the narrative takes place in the nursing home as Emilio continues to have problems with his memory as his AD progresses and he becomes close friends with his roommate Miguel. While Miguel initially mocked those with AD and took advantage of the various residents at the care facility, his relationship with Emilio transforms him and he chooses to remain with Emilio when he is transferred to the second floor where the later stage AD patients live.
Selfhood In Wrinkles

The opening scene in *Wrinkles* showcases how the medium of comics can demonstrate a complicated concept of selfhood. It depicts a young adult Emilio discussing a mortgage with a young and frustrated couple. They appear to be in an office with the sun shining through the window, but then Emilio’s son Juan loses his patience and reminds Emilio that he has not worked at the bank in years and was in fact at home in bed. This does not seem to be the first time this has happened as his son Juan shouts, “This is infuriating, Damn It!!!” and that Emilio had made them late again (Roca 1). The perspective widens to show the trio in their actual environment of Emilio’s room with him in bed. Emilio himself shifts as well, appearing younger with no wrinkles and dark haired in the first row of panels, to turning grey and wrinkled in the second row. Though Emilio does not speak, his facial expression shows that he is clearly surprised to find himself here and then closes his eyes in frustration as Juan continues to complain. Will Eisener in *Graphic Storytelling and Visual Narrative* argues that humans are already hardwired to form empathy and gain information from visual cues from facial or body movements or gestures, so comics can utilize this to connect with the readers and allow the readers to understand relationships or the characters’ experiences (Eisener 48). The reader is able to understand Emilio is feeling frustrated and embarrassed at his memory shift without needing any dialogue. This scene is also critical to showing Emilio’s temper. In response to Juan’s complains, Emilio throws his soup at him, telling Juan that he can just leave. Through these images, Emilio’s concept of selfhood is clearly altered as he realizes where and when he is, and through this realization, also understands that his own sense of time and environment are no longer trustworthy.
Applying Licia Calvi’s argument that viewing comics and hypertext together can help “develop an aesthetics of hypertext reveals many similarities between the two forms (135).

Rather than focus on Calvi’s argument on aesthetics, this paper will note her points of comparison as a means of viewing these AD neurocomics through the lens of hypertext. This moment in Wrinkles connects to her point on analytical montage, or the technique of separating what could be covered in a single panel, into multiple panels. She notes that these moments slow and fragment the scene, while also showing more motion and details (Calvi 135). Looking at this scene through the lens of hypertext emphasizes Emilio’s split selves as he becomes his past self, only to realize that he is no longer that person and no longer in the place or time. Venkatesan and Saji argue that “In the field of graphic medicine, autobiographical narratives on mental illness find expression through the unique semiotic nature of comics, which facilitates the encapsulation of complex psychic-scapes and embodiment of the artist’s experiences” (37). These scenes are very important as they are “translating the sufferer’s altered mental perspective effectively for the reader… which provide a depth beyond the raw medical discourse” (Venkatesan and Saji 37-38). Rather than simply stating that Emilio is having problems separating reality from memory, this scene shows what the experience is like from his perspective to emphasize the jarring shift back to the current events and the frustration and embarrassment that comes with that shift.

Emilio’s fragmenting memories are more than simply forgetting the events, in this scene, it is forgetting all of the time that has passed between the events, even altering his own perception of his appearance.

Emilio’s memory continues to rapidly decline in the nursing home, but there are still several aspects of his selfhood that remain. He clearly associates his sense of self with his career,
regularly acting like he was still working at the bank and referencing his job to other residents. However, he is not always aware that he is no longer working at the bank, though he acknowledges Miguel when he points this out. This example shows the difficulty in describing Emilio’s AD symptoms as linear and progressive, as there are scenes when he clearly knows where he is and that he no longer works, but there are other scenes where, despite being corrected, Emilio immediately forgets again and asks for a ride into town for work (Roca 75-76). Emilio takes pride in his appearance by always wearing a suit, but slowly he starts struggling with dressing and getting the correct order of his clothing. While Miguel initially ignored Emilio when he was struggling, he begins to help by double checking his outfit in the mornings and writing tags on his clothes to help him remember what they are and where they go (Roca 80).

This loss of independence does not relate to a loss of selfhood. While Emilio relies heavily on Miguel for basic needs, his sense of humor remains intact as he steals Pellicer’s news clippings on winning his bronze medal because Miguel hates listening to the story and Pellicer forgets that he has told it before (82). This scene in particular is only effective through comic as Emilio never comments that he was the one who stole it, but his smug and amused expression convinces Miguel that he was the one responsible, causing him to howl with laughter. These little vignettes are critical to showing that Emilio’s sense of self and his individuality are not gone, even as he struggles to complete basic tasks. As McCloud notes, the reader of comics is a “conscious collaborator” to create closure in comics, not unlike how the hypertext reader must also take an active role to progress through a hypertextual work (McCloud 65). Viewing these fragmented moments within the narrative through the lens of hypertext combat closure as Emilio is clearly showing signs that his AD is impacting him, yet his personality and sense of selfhood
remains. The reader must acknowledge both that Emilio is struggling with basic tasks and memory, yet also Emilio is still clearly himself, even if he occasionally struggles with delusions. Benjamin Fraser argues that this scene also emphasizes how the narrative of *Wrinkles* focuses less on the illness itself and more about the experiences of living with AD (Fraser 142). Neurocomics show how relationships can still be developed and that life continues for an AD patient, even if it has changed tremendously.

Another way the work emphasizes living with AD rather than just the losses of AD is through the character of Miguel. The reader may initially view *Wrinkles* as Emilio’s story because the narrative begins and ends with him; however, through the comic medium, there is a dual narrative of the character of Miguel. While Miguel does not have AD or any clear form of dementia, he is still living in the nursing home. Miguel is cruel; he steals money from Emilio, claiming that it was a fee for providing a tour, and clearly steals money from other residents with dementia despite reprisals from other residents and staff. He openly mocks the residents’ delusions and feels no shame in taking advantage of them, especially those who are wealthy. Miguel introduces Emilio to a small group of seniors who all eat together and who become Emilio’s friends.

In an interview with Esther Claudio, Roca described *Wrinkles* as an adventure story about two friends (Claudio 135). He explains that if he were to rewrite the story, he would focus more on Miguel and his growth as he becomes a carer for Emilio because he has since spoken to many carers who go through similar experiences as Miguel (Claudio 135). Initially, Roca was drawn to the idea of the horror of AD, slowly losing yourself over time, but instead *Wrinkles* became focused on the relationship between Miguel and Emilio rather than just the illness (Claudio 135).
Miguel transforms from someone who steals and openly mocks those with dementia to caring for Emilio. As Emilio begins to struggle with basic tasks, the point of view shifts more predominantly to Miguel and the reader follows him after Emilio is taken to the second floor. This shift between main characters creates a dual narrative that shows the impact of Emilio’s relocation on Miguel. Through the dual narrative, Wrinkles continues to complicate the linear progression of the story as the section of the narrative that focuses on Miguel alone has no sense of time, but this also serves to continue to de-center Emilio’s AD from the main narrative. Rather than viewing Emilio’s growing needs as a burden, these scenes show how much Miguel has come to care for him as a person and friend. The scenes that follow show Miguel’s fragmentation as well as the scenes jump in time and location and have no smooth or connecting transitions compared to the Emilio-centered narration. Fragmentation is much more common after Emilio has gone to the upper floors as the narrative breaks between the dual narrative of Emilio and Miguel, patient and carer, and expands into the lives of the other residents.

Social Aspects Of Selfhood In Wrinkles

An important parallel that slowly develops is between Emilio and Miguel and Dolores and Modesto to emphasize the role of carer. Dolores, like Miguel, does not have any form of dementia, but chooses to stay to help her husband Modesto who is heavily affected by the disease. Initially, Miguel mocks the couple and doesn’t understand why Delores would be willing to give up her independence to stay with Modesto. He calls her decision to move to the second floor, an area reserved for patients in the late stages of AD, “suicide” though Antonia argues that Miguel cannot understand because he doesn’t love anyone (Roca 66). Miguel has
regularly bragged about not having family as he doesn’t see the difference in having or not having family when patients with family members rarely see them for visits (Roca 30). Despite this disregard for families, Miguel is notably upset that Delores and Modesto will no longer be with them. This group of seniors are often depicted sitting with each other and this makes the absence of Delores, Modesto, and later Emilio, all the more heartbreaking. The emphasis on the empty seats by zooming in and out of the scene both isolate Miguel and show how he and Antonia are the only remaining members of their group. Reading this work through the lens of hypertext showcases the de-centering of Emilio as the main character through the social network he creates, but also through the presence of the other residents he does not directly interact with. Even if the characters never had dialogue or are not heavily featured in the main narrative, characters can be seen within their memories such as Modesto, who never speaks, but the reader is able to enter into his memory of first meeting Dolores.

Through the layout of the comic, while the main characters may be presented near the center of the panel or in front of the panel, the other characters still appear as unique characters, rather than as part of the background. As Landow states, “hypertext similarly emphasizes that the marginal has as much to offer as does the central” (123). Re-reading Wrinkles, shows that a number of residents that do not have dialogue within the narrative slowly disappear either to the second floor or because they have passed. Fraser argues that these scenes show that it is “social framework and this interdependence that gives our lives meaning” (168). The empty seats also show the loss of the missing people, suggesting that even with the deterioration of their memories, they still had personhood and their absence is felt, even if they were not always conscious of where they were.
While the interrelationships between the different residents is important, as Roca noted, the main narrative of *Wrinkles* is the growing friendship between Emilio and Miguel. An important aspect of Miguel’s transformation in his feelings towards Emilio is his body language. He regularly turns away from Emilio if he is struggling with something and only interacts with him with the group. However, as the narrative continues, more and more panels show them interacting with each other alone. When Emilio asks for help to avoid being moved to the second floor, Miguel starts to interact with him with growing intimacy. DeFalco argues that works like these “…have the potential to challenge the disembodied, independent “I” of autobiography in their depiction of caregiver and care-receiver’s life stories as irrevocably intertwined, interdependent and mutually constitutive” (DeFalco 237). While Miguel originally disparages the caregivers on the first floor, he gradually begins to interact with Emilio and help him. The final scene of them together, where Miguel helped Emilio dress, is particularly telling of the change in relationship between the two. This scene is the opposite of the first time Emilio struggled to get dressed, as then Miguel turns away and quickly removes himself from the room. In this scene, Miguel watches Emilio struggling and choses to act. The last two panels showing their closeness reveals their love for each other. Emilio’s expression is particularly interesting as he seems to be completely content with Miguel helping him while he had previously been frustrated and angry at those interfering, throwing soup at his son and a book at the wall.

For Fraser, scenes like this allow the reader “opportunities to actively construct the story-world through the gaps that are so crucial to the structure of sequential art” (Fraser 169). The reader must not only fill in the gaps in the gutter between panels, but also be able to compare this scene to the previous interactions between Miguel and Emilio as well as Emilio’s often angry
responses to help compared to this grateful acceptance. This neurocomic emphasizes the dual narrative between the progression of Emilio’s disease and Miguel’s change of character to become his friend and carer. At first glance, this scene may appear to be a straightforward sequence of events, except for the final panel that is nothing but blank space. This blank space separates this panel from the smooth transitions of the others and makes it unclear if this act became a daily event or how much time has passed between this blank panel and the next page. This lack of time is not clearly connected to Emilio or Miguel, but makes the transition to the next page particularly jarring as, despite Miguel’s help, Emilio continues to struggle and is moved to the second floor for more care. The page turn also shifts the perspective to Miguel alone, but through Miguel’s gaze, the blank space where Emilio had been remains a clear focus of the panel, again emphasizing that even in absence, Emilio still has a presence in the narrative.

This turning point in the neurocomic emphasizes the dual narrative as Miguel becomes the main character. Rather than viewing Emilio as a burden, becoming friends with Emilio has clearly changed Miguel’s perception of the other residents and himself, showing the devotion of AD patient carers. Roca shows this transformation with Miguel atoning for his previous actions with the residents. While this collection of panels and the later epilogue scenes, may feel unrelated to the main narrative, reading this through the lens of hypertext again supports the decentering of the main character of Emilio to allow Miguel and the other residents their own space. While it may not reach Landow’s “dissolution of centrality” as Emilio and Miguel have the most space in the neurocomic, these moments where other residents are featured complicate what appears to be a straightforward narrative (123).
The final panel of Miguel alone still includes references to Emilio, again showing that his absence is still a way of keeping him part of the narrative rather than removing him from it. The panel shows Miguel staring at the Emilio’s empty bed as he sits alone at the end of the day, shown through the darkening room. Despite his atonement with the other residents, Miguel clearly misses Emilio. While there are more traditional clinical moments in Wrinkles such as the scene where Emilio meets with the doctor to get his diagnosis and the various tests Miguel helps him pass, the more powerful scenes in this work are expressed in the humanistic and emotional scenes. Though Miguel is fully aware of what the second floor is like and how impaired Emilio will be in the future, he is unwilling to continue to live on the first floor while Emilio is on the second. In this scene, Miguel makes the decision to join Emilio. Despite the way the second floor is depicted, Miguel is prepared to join him which supports DeFlaco’s argument that “Graphic caregiving memoirs counter the disavowal of embodiment that marginalizes anomalous bodies by publicizing and humanizing bodies in need” (DeFalco 225). Wrinkles allows the reader to get to know Emilio first and watch his friendship with Miguel develop. Through the medium of comics, the readers can both read and see Emilio’s struggle with AD and become sympathetic to his struggles, becoming carers alongside Miguel. AD neurocomics are particularly important to emphasize the personhood of the patient as their disease is progressive, so their symptoms will only increase, as seen in their final interaction together.

The fragmentation of AD is clearly seen in the final interaction between Miguel and Emilio. Miguel has chosen to move to the second floor to help Emilio, but when Emilio looks up at Miguel, his face initially appears blank. The next panel shows that a few more details of his face return and the final panel reveal his face in full detail. Emilio smiles at Miguel, but as he
looks down at his dinner, the panels show Miguel’s face fading again until the last panel has his face almost erased. McCloud argues that faces are one of the most universally recognized aspects of characters regardless of how detailed or abstract the face and the reader is still able to recognize the silhouette of Miguel (31). While there is undoubtably loss in Emilio’s recognition of Miguel, the final face does have one recognizable feature: a smile. While Emilio has lost the context of his relationship with Miguel, the fact that the smile remains suggests that Emilio is still able to connect affection with Miguel. While the faces shifting in details do imply that even this will fade, Miguel is able to keep their relationship alive. Fraser argues that scene also helps the reader gain “an appreciation of his struggle through a metaphor for cognition made visible on the page” referring to how Miguel’s face fades from recognizable to undecipherable and back (Fraser 166). The shift back and forth between recognizability links back to Emilio’s moments of clarity throughout the narrative, indicating that he is still remembering Miguel, even as the memory fades in and out of existence. While Emilio has been moved to the second floor and continues to struggle with his memory, there are still parts of his memory that remain. This final scene helps fully connect the parallel relationship between Dolores and Modesto, emphasizing that relationships with others helps sustain selfhood even as memories fade.

Environment In Wrinkles

While the character’s features are critical to determine their state of mind, the backgrounds and environments of the panels also provide unique insight into the characters’ feelings. The images in Wrinkles are even more important as there is no narrator in this neurocomic, so the only text provided is in the dialogue of conversations with the main
characters or conversations they overhear. The advantage of the comic medium is in the visuals, such as this moment when Emilio is clearly isolated from the rest of his family as they make decisions about his future without consulting him. Emilio can be seen through the window of the office, standing alone in the hallway with nothing but a suitcase. Moving down the page, Emilio’s head slowly sinks down and he begins to slouch, creating a defeated stance. Even more tragic, the family is explaining that they will likely not even visit him very often. Each dialogue bubble of this discussion is associated with Emilio shrinking further into himself. Venkatesan and Saji argue that regardless of the detail of the body, these postures are universally recognized and help the reader empathize with the characters (42). In this scene, Emilio’s lowered shoulders and head looking down, shows his unhappiness. His location of being alone in the entranceway while his family talks about not visiting him in the other room also accentuates his loneliness.

The colors in this scene are important as well as the offices are a washed out yellow compared to the richer pink of the outdoors, fading into the gray of the floors. The trees shown outside may also provide a timeframe; this is clearly taking place in the autumn due to the falling leaves, but may also represent Emilio’s memories fading along with the leaves. The last panel emphasizes Emilio’s isolation as it takes up the width of the page to show the clear separation between the office and Emilio standing alone in the entranceway. The bright colors of the outside fade after Juan and his wife leave, but it is important to note that there is one bright frame with the color of the outdoors in this scene and that is in the panel where Emilio meets Miguel, foreshadowing their relationship. While these details are lost on the characters in the moment, the reader can utilize the clues of the environment to actively engage in the reading process and fill in the gaps between images and between the limited dialogue.

100
Colors and changes in the environment also inform the reader about the passage of time. Though Roca does not specifically disparage care facilities, the environment depicted in *Wrinkles* does not clearly endorse these facilities either, especially in regard to the daily activities and in the depiction of the second floor. Though there are some variations in daily activities, repetition is a major aspect of the care facility. Fraser notes that the reader has a very limited sense of time in *Wrinkles*. There are shifts in the seasons seen in the outside scenes or through changes in windows, but this lack of time context adds to the feeling of repetition of daily life in the care home. In a two-page spread, Roca shows the course of a day in a single room through the combination of a clock and a shift in the light from the windows. The residents sit in their chosen spot throughout the day, leaving only for meals and sleep, with one of the few residents in a wheelchair, moved solely by the staff and always the last to be moved. Fraser notes that time is measured by appearance and disappearance more than movement as the resident in the wheelchair is the only resident shown moving in this scene and she is also unable to do so under her own power (153-154). He argues that this setup allows the reader to gain an understanding of time through the perspective of an AD patient, rather than experiencing time fluidly (Fraser 154). Reading this scene through the lens of hypertext continues to fragment the narrative as these moments are not clearly connected in time, and while the reader may be able to note hints of time passing through the environment or references in the dialogue, even noting the progression of time requires an active engagement with gap filling. While the reader is aware of the clock, the position of it makes it impossible for the sitting residents, except for the person in the wheelchair, to note the passing of time, creating a unique viewpoint for the reader.
The other main area, the second floor, shows a clear contrast to the rest of the rest home as it is not only more monochromatic, but also more chaotic. The shift in the page’s construction is a much more confusing layout compared to the rest of the neurocomic and this structure is another way in which comics can depict the experience of AD (Venkatesan and Saji 39). The panels depicting the second floor are different shapes and sizes compared to the uniform shape and size of the first floor. Every panel has movement or dialogue, and it is often difficult to see where the patients are in relationship to each other, making the basic layout of the room more difficult to understand as well. The panels shift to multiple patients and show several scenes happening at once, but each are disconnected from each other. The second floor represents a source of fear and pity for the residents and this section showcases several stereotypical images of AD patients confused, crying out, or staring. The speech or sound bubbles often do not connect to a particular person and add to the overall confusion and chaos in this scene.

The colors of the walls and floor are even more washed out compared to the first floor which adds to the overall feeling of hopelessness. The few windows that are depicted also show no color outside and only a single bare tree branch. A woman tries to pull on Emilio’s arm and Miguel has to wrestle him away from her. Patients stare at full plates and think that there is nothing there, despite staff members assuring them that there is food. A patient rocks their head back and forth without any clear reason why. Another patient stares into space. This particular person resembles the example McCloud gives of dementia in Reading Comics, with a wrinkled forehead and half-closed eyes (131). As comics can pull on stereotypes or culturally recognized standards or symbols to provide background information without needed textual explanation, the reader would likely recognize who this floor is for without needing context While this is the
reality of some care facilities, this scene also allows for an opportunity to challenge and complicate what late-stage AD looks like and how people with late-stage AD can be treated. As Czerwiec et al. argues, comics allow readers an opportunity to discuss things that make us uncomfortable in a safe way, in this case, through the narrative of Emilio and Miguel. While Emilio eventually had to be moved to the second floor, Miguel joins him rather than leaving him alone. Though there are still yells and some chaos on the second floor during their final scene together, there is also a sense of peace as Miguel chooses to help Emilio and remain with him, even as Emilio struggles to remember Miguel.

Another place where residences may experience peace is through their memories, and because memories are shown as occurring in real time in Wrinkles, through work’s layout, the reader is the only one privy to both the current events and what is going on in the residents’ memories. While in a memory, the characters appear slightly differently. The character’s face shifts to fit with the memory of their younger selves and their clothing styles change as well. Mrs. Rosario is depicted with white hair in a bun, sitting in a wheelchair wearing a green sweater over a yellow shirt and a dark skirt. In her memories she is still depicted with the bun, but with dark hair and a luxurious fur coat. Antonia has an even larger shift as she is normally depicted with short white hair in a green sweater with a walker, but when she chooses to join Mrs. Rosario, she has long blonde hair and a red coat with black trim on the collar and cuffs (92). The reader needs to see the first two panels of this page to understand that this character is Antonia. This page is also the only time that a character is able to join another character in their memories. The panels get larger and less confining as Antonia approaches Mrs. Rosario, suggesting the importance of social connections to alleviate the isolation of AD. Fraser points out that this is
only the second time two characters are included in the same memory, as Delores and Modesto have the same memory of the day they started dating, but this event is unique as Antonia and Rosario don’t share this memory. Instead, Antonia is joining into Rosario’s memory and experience on the Orient Express just as the readers have been able to join the other characters’ memories (Fraser 168). Both of these characters can escape the dull pale colors of the retirement home and escape into the richer jewel tones and landscape of Mrs. Rosario’s memory.

The smoke from the train in the final panel leaves the panel open, emphasizing this feeling of escapism. While discussing Thompson’s *Carnet de Voyage*, Davies notes that enclosures of panels disappear when “emotions are exposed” to the reader and the panels only return once the narrator has calmed down and returned to the main narrative (Davies 127-128). While the emotions are less extreme in *Wrinkles* this open panel helps further separate the memories from the present and show more emotion compared to the majority of the other panels with these characters. Fraser argues that the medium of comics supports “the idea that even those who seem unable to tell stories are narrating themselves long after many suppose they have stopped doing so” (Fraser 169). By allowing the memories to take up and have the same weight as the current events of the narrative, Roca is showing that the resident’s selfhood is still very present, though difficult for others to always access.

While this genre may not be feasible for all AD patients to express their narratives, it does show that selfhood may be expressed in different ways and through these stories, allows the stigma of AD to be lifted. In *Wrinkles*, while these residents slowly lose their sense of selves, this fragmenting is not always seen as a terrible thing as the AD patients’ memories are shown in bright, rich colors compared to the dull experiences they have at the retirement home. Even when
they are physically absent, their presence is still noted and though their social bonds, their
memories are carried through others, even when the AD patient is no longer able to express it
themselves. Miguel is also transformed through his friendship with Emilio and sees Emilio’s
selfhood, despite his increasing impairments due to AD. Reading *Wrinkles* though the lens of
hypertext clearly reveals the network of connections between the residents, the de-centralization
of AD as the focus of the work, and the complicated multi-linear timelines represented within the
narrative.

**Tangles Summary**

While *Wrinkles*, combines several of Roca’s nursing home stories together in a narrative,
in Sarah Leavitt’s 2010 work *Tangles*, Leavitt confronts her mother’s diagnosis with AD, the
progression of her illness, and mourning her passing. *Tangles* was a finalist in several awards for
graphic novels and comics and did win the CBC Bookie for Best Comic or Graphic novel. The
work focuses on Leavitt’s mother, named Miriam but always referred to by her nickname Midge.
Midge was afraid that she had AD and it took months of fighting against her family’s concerns,
before she acknowledged that she had some memory issues. As Leavitt lives in a different state,
when she visited, she would record her interactions with her mother as both a form of record and
as a coping mechanism. Midge was ill for six years before she passed, and Leavitt collected her
drawings and journal entries to create this work. For Leavitt, she wanted to remember her
mother, “as she was before she got sick, but also to remember her as she was during her illness,
the ways in which she was transformed and the ways in which parts of her endured” (Leavitt
“Introduction”). While this work focuses on Midge’s AD and her fragmenting selves, it also
addresses how Leavitt also became fragmented as her mother’s diagnosis forced her to “reconsider [her] identity as a daughter and as an adult” and also her relationship with her mother (Leavitt “Introduction”). *Tangles* weaves together the narrative of Midge’s illness, how Leavitt and her family copes with the changes that come with AD, and trying to negotiate her memories of her mother with mother’s progressive illness.

**Selfhood In Tangles**

As *Tangles* is written in Leavitt’s perspective, Midge’s selfhood must be seen through her interactions with her daughter. While the work does focus significantly on Leavitt’s experiences, there are moments that focus on Midge, though the reader must assume that Leavitt portrayed this moment accurately. The pages that are dedicated to Midge are unique in that they are completely white except for a single drawing that occasionally comes with dialogue. Landow argues that hypertext “redefines not only beginnings and endings of the text but also its borders…” (113). While structurally not a hypertext, by viewing *Tangles* as having these blurry borders within the works, these moments provide an opportunity to break the linear narrative, but also re-center Midge as the main character of the story, even if Leavitt is the one narrating and drawing. Davies argues that borderless space in Thompson’s *Carnet de Voyage* is a way for the author “to ‘reach out’ to the reader, to represent a ‘candid’ or direct contact” (Davies 127). Applying this argument to *Tangles*, provides a means to focus entirely on Midge and provide her a space that belongs entirely to her. The white spaces in *Tangles* serve as a way to create a pause, what DeFalco refers to as “loiterature,” and allow the reader an opportunity to see Midge, with limited intervention from Leavitt (236). DeFalco argues that these pages remind the reader of
Midge’s own distinctiveness, while also acknowledging that Leavitt is the sole creator of the text, again exemplifying the dual narratives of patient and carer by allowing Midge to have her own space (234).

The two white sections separating the parts of the narrative reflect Midge’s deterioration and fragmentation of herself. In Chapter 1, I discussed Lindsay Starck’s metaphor of a stereoscope to describe memory and offered a kaleidoscope as a means to view memory with AD patients. This metaphor seems particularly apt for Tangles as well, especially with these images that are both part of and unique from the main narrative. The first image depicts Midge expressing frustration at her situation as she states, “I hate what’s happening to me” (Leavitt 42). On this page she is looking off to the side and has her hair in a ponytail with just a few loose strands. Her hair reflects her fragmentation as she is still cognitively aware and able to recognize that these changes are happening, so her hair is mostly neat, but she is unable to stop AD from progressing as the few loose strands show. In the page before Part Three, she is shown responding to someone’s, likely Leavitt’s, question of “How’s it going, Mom?” and she responds with, “Oh, I think it’s going quite sadly” (82). More of her figure is seen here and her hair is loose and slightly messy, representing further loss of her cognition, and her head is to the side and looking down with her eyes closed. Her arms are clasping at her waist, a pose that she takes several times throughout the work. While she is smiling, with the combination of her eyes closed and her posture, this version of Midge appears sad. By marking the beginning of each section with an open panel just focusing on Midge, these pages work to re-center Midge as one of the central figures, even though she is only portrayed through Leavitt. It also serves to immortalize the multiple selves of Midge as she comes to terms with her illness, progressing through anger to
depression. Her solo occupation of this large white space also “emphasizes the distance and isolation imposed by her disease” without requiring text or narrative to express the impacts of AD on Midge (DeFalco 234).

These interludes also complicate the timeline in Tangles. McCloud argues that many readers assume comic narratives are organized linearly and time may be organized based on panel construction (100,106). While Tangles includes some flashbacks, it is implied that this narrative is organized linearly as the narrative starts with Midge’s early symptoms and her diagnosis and ends with her death. However, these brief interludes that focus entirely on Midge are unique compared to the other panels. They have no borders and no or limited backgrounds making them appear to exist outside of time within the narrative. Reading this work through the lens of hypertext requires the reader to put these works both outside the narrative and yet still within the timeline of Midge’s illness. By removing any time stamps and also removing any background details that may have provided a sense of environment or time, these panels serve as a representation of Midge’s selfhood. Though these moments were selected by Leavitt, they show Midge’s range of emotions from her jokes, recreation of her loving notes, but also the progression of her illness and her resulting loss. An example of this loss is the scene where she wants to join the family, but forgets to pull up her pants after using the bathroom, so she shuffles forwards with her pants around her ankles (Leavitt 47, 99, 81). Through the lens of hypertext, these selves exist all together, but also show that aspects of Midge’s personality, wanting to be around her family for example, still exist even as she struggles with basic tasks. These scenes show the importance of physical bodies and Leavitt does not hesitate from showing the physical changes that AD has wrought in her mother. The comic medium is particularly useful in
displaying Midge’s experiences with AD as her symptoms wax and wane, but slowly continue to grow worse. Within the comic, Midge’s multiple selves all exist in the same place and are impacted by the memories and interactions with Leavitt and how Leavitt wants to remember her mother.

**Social Interactions In Tangles**

Though the narration of *Tangles* is told through Leavitt, by reading this text through the lens of hypertext, both the author and the patient have distinct voices and experiences as they cope with the changes brought on by AD. Landow notes that hypertextual works can have a linear storyline with “self-contained stories” made from following different narrative “loops or pathways” (210). While *Tangles* is not a hypertext that allows for multiple endings or pathways, reading this work through the lens of hypertext allows for these “self-contained stories” to appear in the white pages where Midge has her own space within the narrative and with moments where Midge becomes the main character, creating this dual narrative of Leavitt’s experiences alongside Midge’s experiences (albeit told through Leavitt’s comic). Leavitt shows the fear and anxiety surrounding a diagnosis of AD using panel size, text type, and white space. In this scene, even though Midge is sitting between her daughter and husband, in the middle panel, she appears alone surrounded by the doctor’s questions in large, bolded text. Her hands are clasped against her chest with her heels together and she looks very small compared to the white space in the panel that takes the entire width of the page. The doctor appears frustrated in the next panel, indicated by his hand resting against her forehead with the text “hmm” like he was thinking. The reader can only imply that Midge did not answer the questions as there are no panels indicating
that Midge has responded. Instead, Midge asks about her headaches in the next panel and is ignored by the doctor who directs his questions to her husband Robert. The comic shows Midge’s annoyance at being ignored by showing her arched eyebrows and frown. The doctor’s barrage of questions for Robert on Midge’s behavior looks similar to the panel depicting Midge’s questions; however, while he also shown to be alone despite sitting next to his family, the white space is considerably smaller, matching the other panels in size. The difference in size indicates Leavitt’s feelings that her mother seemed more attacked and isolated compared to Robert.

The advantage of the comic style in this scene is to show how overwhelming this experience was for the family and how disconnected they felt from each other and from the doctor. Unlike in the large white space sections where Midge is alone and the reader is more likely to pause, the placement of her in the middle of the panel surrounded by the questions hanging in the air in thick black lettering shows her as diminutive rather than controlling some of the space. While Robert tries to shift the conversation back to Midge to allow her to speak on her own behalf, the final panel of the page shows the trio in black and disconnected from the frame as they are asked even more questions from the doctor. This disconnect from the panel is also noted in the penultimate panel as Robert tries to involve Midge in the conversation, but she just stares at the ground instead, completely disconnecting herself from the conversation. This scene is very similar to Emilio’s first day at the care center in Wrinkles, as the comic showcases the increasing isolation of the AD patient, even when they are surrounded by their family. Unlike Emilio in Wrinkles who must create new bonds in the care facility, Midge does have support from her family, and she does get regular visits when she is in a care home, but even with the large amount of support, she is still isolated.
The impact of having a loved one diagnosed with AD is complicated and one of the greatest strengths of Leavitt’s comics is to show multiple levels of emotion at once. This is seen when Leavitt attempts to interview her mother about her diagnosis and experiences with AD. Initially, her mother is happy to participate and this is shown in her body language as she sits close to her daughter, and while both are crying, she has little hearts around her face. The next panel has the word “BUT” written out and shows how Midge was unable to respond to the questions. While Midge wants to share her stories as she states, “I don’t want there to be any secrets about my illness,” she was unable to respond to Leavitt’s questions, growing quiet and angry (Leavitt 55). This entire page shows the range of Midge’s emotions over the interview, showing her as Leavitt remembers her as a loving and supportive person, but becoming more angry and quiet through the progression of her illness. This anger can be caused by the disease itself or due to her frustration of being unable to communicate.

Leavitt’s face is also drawn in a variety of ways within this page, showing her own range of emotions as she tries to communicate with her mother. McCloud argues that even squiggles can translate into emotions if they are universally recognized (131). Though some of these emotions like a teardrop can be recognized immediately, some emotional readings take more effort and show how simple additions to facial features in comics can depict more complicated emotions. The first panel shows her emotional, but happy feelings about being able to interview her mother compared to a later panel showing a fake smile, trying to lighten the mood as her mother grows angry watching the footage. Chute argues that comics can merge the internal and external realities together to “capture a concept otherwise too abstract to articulate” (268). The looks of concern from the daughters as their mother starts to frown shows not only their
discomfort at their mother’s reaction, but also their confusion as she initially agreed to be interviewed. The next panel has no words at all, but Leavitt’s face is shown with tears and a triangle squiggle above her head showing that she is both sad and angry. Her arms are crossed, and she appears to be alone on the couch, despite the following panel showing that she is next to her family. Her feelings of frustration also lead to feelings of isolation. Midge then shifts back into her positive self, and instead of being pleased at the praise, Leavitt leaves to eat gummy bears in the attic and throw herself back into chores. This page shows the constant shifting in emotions for AD patients and the struggles of the family members trying to connect with them. 

This scene is particularly poignant in showing the coping strategies of the different family members. Leavitt is still trying to connect to her mother, but her mother gets frustrated towards what she sees as condescending behavior, and even when her mood shifts and Midge becomes more positive again, Leavitt has to remove herself or engage in a different activity to cope with the stress. Her sister Deb distracts Midge by shifting topics and focuses on puzzles as a way to separate herself from the stress. After viewing the footage together, the characters are no longer in the same panel together, but in smaller panels alone. As there is limited dialogue and no narration, these scenes rely on facial features and body language to clarify and develop what the text is implying. Through the comic medium Leavitt is able “to demonstrate the subjectivity of disabled characters by having their images occupy the page as emphatically as their caregivers” (DeFalco 237). Rather than displaying her mother as a burden or lessening her as a person as her body and memory start to fail, she and Leavitt both have a clear presence throughout the work. However, this scene also shows the separation of the family even within a
shared space, emphasizing the isolation of the AD patient, but also the disconnection family members feel, even when they are trying to help.

Leavitt’s relationship with her mother continues to evolve as she helps her mother bath, change, and go to the bathroom. In several scenes Leavitt imagines her physical body changing, even depicting herself as a monster, as she tries to negotiate how the changes in her mother have caused changes in herself. She even attempts to disassociate herself to adjust to this change in relationship. As Leavitt lives in another state, she normally spoke with her parents over the phone. During one of these calls, Midge asks Robert to leave and tells Leavitt that she doesn’t want to be married any longer. Leavitt immediately notes that she has never discussed any marital issues with her mother, but rather than focusing on Robert, Midge yells, “I’m a nobody!” and in the next panel, “I’m not a real person anymore!” (Leavitt 67). These panels don’t show Midge’s body, but instead show the phrasing in spiked word bubbles. The first quote is shown coming out of the phone, while the second is shown in only the spiked word bubble with a black background and in bolded larger text. While the comic could show Midge speaking on the phone, this page represents Leavitt’s experience with her mother and what is going on in her mind during this conversation. Midge starts to cry and explains to Leavitt that Robert is treating her like a child and she only wants independence (Leavitt 67).

Here Leavitt’s process of fragmenting is shown as she appears in three different versions of herself within the same panel as she comforts her mother. While her face is shown to be calm as she allows her mother to talk and then promise to speak to Robert about her feelings, it is clear that Leavitt is struggling with this new relationship between herself and her mother. The final panel shows her true feelings as she shifts from a lotus position, body posture matching her calm
and controlled tone, to a blacked out figure having a tantrum on the floor yelling “WAAAH! I want my mommy!” (Leavitt 67). The “WAAAH!” breaks out the panel and overlaps with the previous row of panels showing her three selves as she speaks to her mother, suggesting that this is what she was actually feeling the entire time. Davies argues that “dropping or exceeding panel borders seems in graphic narrative to connote immediacy, starkness, directness” and when “a character ‘reaches out of the page’ when they are drawn outside of borders; at moments of shock or extreme emotion, a character may be drawn reacting without background or border to contain them: they are ‘exposed’” (127). Leavitt is unable to contain her feelings that she doesn’t want to be put into this role even as she does what is needed. These inner feelings are so strong that they break through the panels and are in a different text front from the rest of her dialogue. While Leavitt is able to help comfort her mother, these panels allow her to also express her actual thoughts alongside her dialogue.

This page also includes a story of Leavitt’s close friend’s grandmother had killed herself after looking up the symptoms of AD, showing how outside experiences directly impact Leavitt’s mental state. Nick Sousanis argues in Unflattening that the mixed modality of comics may be a better method of displaying how complex our thoughts really are because the reader sees all the images at once before breaking them down (Sousanis 67). While outside the direct narrative of the main plot, this included memory further complicates Leavitt’s feelings on this page as her friend’s grandmother, who Leavitt describes as “elegant” chooses to end her life rather than go through AD on the same page that Leavitt must take a motherly role to her own mother with AD. Hernández Gonzalez argues that the layout in Emil Ferris’ graphic novel My Favorite Thing is Monsters (2017) “imitates the way our brain works and how we think about
many things at the same time, jumping from one idea to another” through the chaotic structure and lack of panels. Though *Tangles* does use panels to separate the different sections and scenes, this combination of thoughts and interruption of these panels attempt to express Leavitt’s mental state, getting closer to a stream of consciousness, but less chaotic and more limited.

Comparing this moment in *Tangles* to Bush’s concept of a memex provides a new way to view this page. In his famous essay “As We May Think,” Vannevar Bush argued for an early version of hypertext, called a memex, where information is linked by association similarly to how human thought process works. Through the process of coding, the user could combine topics together, organize them by links, and add their own opinions and analysis. Both Sousanis and Hernández Gonzalez argue that comics can provide a means of expressing the character’s state of mind; however, viewing this page in comparison to Bush’s memex provides an insight into how Leavitt thinks, showing both her association of events and how her physical and verbal responses can be significantly different to her emotional responses. This scene is particularly poignant as it shows her connections to an outside event to her mother’s phone call, thinking about the elegant woman who ended her life after her AD diagnosis, and her physical body and responses to her mother as she tries to calm her. While Leavitt appears to be calm and speaks soothing to her mother during the call, her internal thoughts supersede the boundaries of the panels as she is unable to stop these thoughts and feelings. While this still does not meet Bush’s goal of creating “pen-and-ink traces which bear some relation to the electrical phenomena going on in the brain itself,” but it viewing this page in relation to Bush’s memex shows how neurocomics can represent the complexity of human thought and the difficulties in being a family member and carer to an AD patient.
Environment In Tangles

Not only are there emotional tolls in caring for an AD patient or struggling with the impacts of AD emotionally, but there are also physical aspects of AD including medical tests and treatments. The advantage of neurocomics is that they can describe both the medical procedures, while still keeping the patient at the core of the narrative. A diagnosis of AD takes multiple steps and can be very taxing physically and emotionally. The page shows Midge in two different tests, a brain imaging scan and a spinal tap. In both panels, she is shown to be vulnerable and alone, strapped to the machine or waiting for the spinal fluid to be removed. A long central panel shows the variety of blood and test results she has submitted, eventually ruling out every diagnosis but AD. The inclusion of some of the materials or procedures that Midge undergoes is important for neurocomics and comics that focus on illnesses to concretely show the invasion of the body, not only by the illness, but by the medical procedures that diagnosis or treat the condition. Marchetto in her 2006 work *Cancer Vixen* chose to include a drawn to scale biopsy needle alongside a collection cup to emphasize to the readers what the biopsy is like. Marchetto combines realistic drawings of the equipment alongside a cartoon version of the cancer cells, utilizing comics’ ability to combine the real and imaginary elements together to better articulate the experience of the author. Chute argues that comics that focus on illness utilize show and tell “to find a way to depict complicated experience accurately— in both words and pictures alike, and in the spaces of meaning between them” (244). The readers view snapshots of Midge’s various tests and the amount of samples she has to give, but each panel emphasizes Midge in a vulnerable position with very limited agency as they wait for the results. The visual representation of Midge in these
vulnerable positions and her body’s growing frailty (as described in the following paragraph), push the narrative beyond just Leavitt’s experiences. The final panel shows some the largest amount of text providing exposition on the final results, but this also shows Midge and Robert together, Robert with his arm around Midge, showing a united front. While Robert is touching Midge to show his support, her arms are by her sides and they are dwarfed by the text on either side of them, also suggesting the difficulty of Midge’s diagnosis and the beginning of her feelings isolation and being a burden.

*Tangles* is the only work of the three described here to depict the death of the AD patient and provide an insight into the process of dying with AD. Through the comic medium, this passage of time can be told through the environment and the changes in how Midge is drawn. As with *Wrinkles*, Midge is eventually placed within a nursing home when Robert injures himself trying to care for her. While there, she slowly begins to lose her connection to Robert and becomes quieter and less interactive. The series of panels shows the progression of her illness as she initially greets Robert with a smile, but then she starts falling asleep during his visits. Understanding how time flows here becomes even more complicated compared to the rest of the work. As there are no traditional measures of time like a clock or calendar, and limited environmental clues, the reader must make assumptions about the time that passes between panels. Midge’s clothing may provide some hints as she begins in a shirt at the start of the four panels and ends up in a sweater and scarf in the fourth panel, suggesting that the seasons have passed and it is now winter. There are also some changes to how Midge appears and how she interacts with Robert. Midge begins to be drawn with lines on her cheek as she loses weight and she has no responses to Robert in the last two panels of that row. The environment also changes
as she would go in the main room or outside for her visits from Robert, but then she becomes bedridden. Her body also becomes more slumped over, first in her wheelchair, to sitting up in bed, to lying flat in bed.

Unlike *Wrinkles* where the reader can see from Emilio’s perspective with awareness fading in and out, *Tangles* shows a steady decline over time to the point where Midge has very limited interaction with the outside world. The final row shows Midge in increasingly less detail and this trend continues until she has died. This depiction coordinates with Midge’s deteriorating sense of selfhood and identity as she dies. Despite her obvious loss of cognitive ability, there are still moments in her last days of life where she would still respond to kisses or squeezing her hand (Leavitt 119). However, her final moments and the time after her death are drawn in the most abstract version of her in the entire comic with vague features and wavy lines spread out around her head instead of her usual hair, clearly changing the art style and marking her loss of cognition. After she passes, Leavitt cuts locks of Midge’s hair for the family, depicted as a tiny figure reaching towards the abstract head and hair of her mother. In the accompanying text, Leavitt writes that “inside I was screaming” as she cut the hair (Leavitt 122). While the text describes the basic actions of Leavitt cutting Midge’s hair, depicting Leavitt as a tiny figure reaching up to the vastness of her mother’s body shows the impact of this action, the final acknowledgement that her mother is dead. There is no gutter separating cutting Midge’s hair from the rest of the panel which also shows the family gathering to say goodbye and Leavitt leaving the room. This continues to muddle the reader’s sense of time which is a common feeling after a loved one has passed. While there is clear loss depicted in these final scenes, the comic doesn’t end with Midge struggling with her AD. Venema argues that “Tangles’ concluding
lamentation most powerfully demonstrates comics’ unique ability to make absence present” (Venema 678). Even after her death, Midge is present through Leavitt’s mourning and through the removal of her medical equipment and belongings. Initially, this image of Midge after she has died may seem like the final death of her selfhood and her final fragmented form as a result of her illness.

However, the final image of Midge comes from one of Leavitt’s dreams which depicts Midge as her younger self and surrounded by flowers, showing that her memory will be carried through this work and through her family’s memories. Reading this ending through the lens of hypertext complicates the concept of closure. As Landow argues, “…conventional notions of completion and a finished product do not apply to hypertext…” (112). While Tangles does have an ending and the physical text stops, the way Midge is represented towards the end of the work pushes back against a feeling of closure. Supporting Venema’s point, Midge remains present even after her death, emphasizing the impact of loved ones long after they have passed and provides a means for retaining Midge’s selfhood after her death. Leavitt has chosen her version of Midge’s self of the varied kaleidoscope selves to keep as a final memory of her mother. This final image of Midge completely contradicts the how Midge is shown after her death, showing that Leavitt has created the final self of Midge, the one she will carry as her memory of her mother.

The structure of Tangles complicates the linearity of the six years of Midge’s AD through these various selves and page layouts. These large white spaces fight against a linear structure and provide a space that is entirely for Midge, even though the reader is always aware of Leavitt as the author, creating a dual narrative similar to Wrinkles’ structure. The comic layout also
offers moments to express the human thought process and the difficulties of being both a carer and a family member. It also shows the reality of caring for a loved one with AD and the physical toll that the testing and progression of the illness takes on the patient. This neurocomics utilizes its medium to express both the loss and celebration of Midge’s life while also acknowledging the impact AD had on her entire family and how Midge will be remembered.

**Aliceheimer’s Summary**

Similarly to *Tangles*, Dana Walrath’s work *Aliceheimer*’s follows her mother Alice’s progression in her AD, but in a very different style as this neurocomic has a larger gap between the images and vignette stories and uses cut up sections of text from the novel *Alice in Wonderland* to create a variety of images of Alice. This work has also appeared as an art exhibit, a play, and an opera, but for the scope of this dissertation, this chapter will focus solely on the printed version. This work has been praised for its anthropological approach and it is unique as Walrath approaches Alice’s progression through a more fanciful eye, viewing confusion or hallucinations as a magical power rather than a defect in her brain. Ahrens argues in his article on David B.’s *Epileptic* that “the medium of comics manages to cultivate the cohabitation of imaginational and reality-based elements” (Ahrens 85). Applying his argument to Walrath’s work is useful to see how she is able to combine the harsh reality of her mother’s dementia through the lens of *Alice in Wonderland* to both cope and understand her mother’s experience of the world.

Reading this work in comparison to Shelly Jackson’s work, *my body & A Wunderkammer* (1997), a hypertext work that also explores fragmenting the body and memoir, creates several
parallels. Scott Rettberg argues that “Jackson investigates the way that the body becomes a kind of inscription surface for personal history and memory, and how its surfaces, limbs, and organs function both as individual entities and as indivisible aspects of a human subject’s identity” (Rettberg 73). While Walrath’s printed medium limits interaction from the readers, her construction of her mother’s body as a mixture of hand drawn elements with the cut up pieces of *Alice in Wonderland* draws some similarities between the two works. While Jackson’s work allows the reader to click on various parts of the body to connect to unique vignettes, Walrath presents her mother’s body as a whole, but each version of her mother comes alongside a vignette. Rather than exploring her physical body, by altering her mother’s body to this fantasy-driven version, Walrath is able to explore her mother’s mental state and how AD is impacting her daily life. María Goicoechea de Jorge argues that in both Jackson’s famous work *Patchwork Girl* (1995) and *my body* that “The mind-body relation does not emerge from an ontological integrity, but in the immanent and recursive parceling, fragmentation, and reconstruction of the whole, the subject, by a reflexive and creative self through a variety of metaphors” (87). Walrath is able to pull from the fragmentation and confusion inherent in *Alice in Wonderland*, to present AD through fantasy, so Alice’s delusions or fragmenting is part of the fantasy rather than a debilitating neurodegenerative disease. These vignettes may be viewed as Landow’s self-contained stories as there is no clear connection or linearity between these vignettes and while Alice may appear whole in some of these images, she is disappearing or fragmenting in many others. This approach to AD utilizes fantasy to account for Alice’s changes in perception and awareness, which also helped Walrath develop her relationship with her mother and address issues in their past.
Selfhood In Aliceheimer’s

In the section titled “Flight,” Walrath explains that while Alice can no longer complete the crossword puzzles in the *New York Times*, she still loved to play Scrabble and make up her own words (19). Not only did she have the spellings of these new words, but she also created a definition to go with them (Walrath 19). Rather than correct her, Walrath embraced these new words, claiming that no one could challenge Alice in those games. Alice also had hallucinations of her mother, who had died in 1954, but rather than be concerned about these delusions, Walrath describes this ability to see the dead as a superpower. The image drawn beside this text shows Alice flying with her arms stretched before her towards the sun. As with all of Walrath’s drawings of Alice, she is made up of a hand-drawn face and her clothes are made up of cut out sections of *Alice in Wonderland*. The cutting up of the text is particularly interesting when viewing this work in terms of fragmenting, as Walrath physically creates a new version of her mother by piecing bits of paper together. She is not only made of paper, but also connected with drawings providing her features. She has slippers on her feet and her hair is a mix of curls and straight lines that stick out around her head forming a halo around her. Through this re-creation of her mother, Walrath is able to transform Alice and also provide a version of her mother that helps Walrath cope with her mother’s illness. While Walrath does not shy away from her mother’s delusions and the difficulties that can come with them, by approaching her mother’s AD through fantasy, she is able to both address those concerns while imagining her mother as this otherworldly creature, rather than viewing these changes as symptoms of AD. The text above her reads, “She didn’t take off” and finishes below her, “Though she has special powers”
(Walrath 18). Through the use of Alice in Wonderland, “Walrath repeatedly makes from Alice’s forgettings and misrememberings celebration-worthy new realities” (Venema 673). Rather than portray her as a woman sitting in her bathrobe with her slippers, by portraying her hair framed by a halo and the disjointed words on the cut-out paper make her seem otherworldly rather than frail.

The gap filling between this image and the provided narrative is wider than typically found in comic panels as the connected story may be on the opposing page or the image may be the entire story. However, part of Walrath’s reasoning for creating a graphic work was to ensure that someone with dementia could still read it (5). These short instances allow both the AD patient and the carer a moment to escape from the reality of AD and view Alice as someone new and interesting rather than someone to be pitied (Walrath 5). Walrath argues that her goal was to show carers that these hallucinations or loss of memories can make these changes part of life rather than a battle or loss (5). These vignettes exist out of any sense of time. As an AD patient progresses in their illness, their memory becomes more episodic, so this structure may also provide another way to represent the experience of an AD patient. This structure also pushes back the need to have a linear order to the narrative.

Rather than using a linear narrative, Walrath utilizes Alice in Wonderland to understand Alice’s sense of selfhood. She quotes from the text: “I knew who I WAS when I got up this morning, but I think that I must have been changed several times since then” (Walrath 68). This quote from Alice in Wonderland is particularly appropriate for Alice as she experiences what is called the sundowner’s syndrome, or that she has more problems with memory as the day goes on and particularly struggles at night. Throughout Aliceheimer’s, Alice is portrayed as both an
adult and as a child, representing her switching between adult cognition and more childlike understanding. In this image, though her body is portrayed as an adult, she is holding a collection of stuffed animals while she sleeps, representing the duality of adulthood and childhood within the same person. Alice fragments between scenes, but the text also shows how her understanding of time also starts to fade towards the end of the day. In the evening, Alice slips into her memories, especially ones associated with fear and stress, as she worries about Japanese soldiers sneaking in at night or that the family is eating dog meat rather than beef due to ration limitations.

This scene is also the last image of Alice in the work and the title of the vignette is “Who Are You?” another reference to Alice in Wonderland as the caterpillar famously asks Alice who she is, but this is also poignant for AD patients as it emphasizes the struggle to maintain selfhood with AD. Ahrens argues that comics allow the “permanent presence of imagination in reality” allowing this version of Alice to coexist with her dementing self for Walrath (Ahrens 87). Aliceheimer’s is the only work to address sundowning, which helps the reader understand that Alice’s memory is steadily declining over the years she has AD, but also in waves during the day. This is expressed in Wrinkles in the final scene with Emilio and Miguel as Miguel’s face comes in and out of focus. As Tougaw argues, “Graphic narratives blend fantasy and realism to tell particular stories about characters in visual-verbal language. They are explicitly dreamlike and speculative” which allow patients to reimagine themselves or transform their conception of their condition into a different form that makes it easier for them to understand or accept (189).

Applying the kaleidoscope approach to selfhood is also effective with Aliceheimer’s as Walrath views Alice in multiple ways in Aliceheimer’s as she breaks down her daily rituals of teatime,
complies stories of her mother’s childhood and adult life, while also helping her with basic care. While Alice may appear to be struggling in the text, the images keep her otherworldly version just as important as the accompanying text. The medium of comics allows Walrath to portray her mother in a fantastic way with the accompanying text to provide the current reality. Both the images and the text work together to explain Walrath’s experience as a carer for her mother.

Social Relationships In Aliceheimer’s

While Aliceheimer’s focuses primarily on the relationship between Walrath and Alice, there are some moments of other relationships, which help explain Alice’s understanding of herself and others. Not only does Alice struggle with her sense of time, but her understanding of her relationship with her family members does falter, creating more complicated social relationships. Walrath notes that the ability to recognize family members is one of the main components of the “public self” (Walrath 69). She argues that the first question anyone asks after her diagnosis, and even more after Alice enters into memory care, is always, “Does she still recognize you?” (Walrath 69). Selfhood is not only seen as understanding of self, but also understanding of self in relation to others. While Walrath acknowledged that Alice struggled to recall her name, her other guesses indicated that she still understood their emotional relationship. Alice would guess that Walrath was her mother or sister, which Walrath argues shows that she understands that they are family and that Walrath will help her (Walrath 69). While Alice may not have the correct term, the emotional connect that she still has to Walrath combats the stereotype that AD patients lose the identity of their loved ones. While they may not be able to use the appropriate name or title, the emotional connection to this person remains.
This connection to her other relationships remains even if the person had passed, further complicating any sense of time in the narrative as Alice is unable to remember that Dave, her husband, has died. Walrath argues that that when Alice sees Walrath’s deceased father, Dave, up in a tree, Walrath agrees with Alice instead of correcting her. Rather than seeing these hallucinations as a sign of her cognitive deterioration, Walrath presents this as a superpower that adds to Alice’s quality of life. As Jorge points out, in Jackson’s work “the territories of memory and body are drawn and blurred,” this can be applied to Aliceheimer’s as well. In this scene Alice appears in her otherworldly appearance next to Walrath’s drawing of herself, the only character drawn entirely in pencil as is the environment. These pencil drawings reflect the reality of the moment compared to the colorful Dave and the collage Alice. However, as this hallucination of Dave brings Alice joy, Walrath presents this hallucination as the reality. Dave is the only character, other than Alice, to appear multiple times within the work with a total of seven images, though some are repetitions of the same image. Dave is often described as being in a tree with Alice below, which Walrath quips is a good metaphor for their marriage. There is also another separation of the two characters as the fold of the book serves as a separation as well. Venema argues that these moments, “…especially in the collages of Dave and Alice, signal a deliberate disconnection with rational reality and an engagement instead with the profoundly meaningful—and, crucially, emotionally contiguous—world that Alice now navigates” (675). These delusions help Alice and Walrath connect to each other and allow Alice to acknowledge feelings she would not be comfortable doing otherwise. Similarly to Wrinkles, these memories or delusions are made even more vivid compared to the reality of the situation. Instead of making these images something to be ashamed of or viewed as a loss of selfhood, these delusions
become stories, relieving Alice from monotony or shame. Through the combination of Alice’s AD and the comic medium, Dave is alive in her memories and through the narrative, again emphasizing the importance of Alice’s current experiences rather than accuracy or a sense of linearity.

**Environment In Aliceheimer’s**

Discussing the environment of Aliceheimer’s is very different compared to the other two works as this narrative only uses a single image rather than comic panels, so this section will focus on two different depictions of Alice that represent her mental state in the process of fragmenting. The first image shows Alice without a head and only a grin where her mouth would be. The only physical representation of Alice is her clothing as her hands and feet are also missing; the rest of the background is simply dark squiggles. The text above her smile reads, “Alice is disappearing. Soon there will be none” (Walrath 10). The use of the Cheshire cat’s grin provides another connection the reader can form with their knowledge of *Alice in Wonderland*. The image as the Cheshire cat is famous for his ability to shift in and out of sight, with his trademark grin typically the last to disappear. Similarly to *Tangles*, Venema emphasizes this idea that even if the AD patient appears to be disappearing due to her dementia, she is still present (676). The smile can also indicate that not all of Alice is truly gone. Walrath notes in the adjoining narrative that while Alice was no longer able to live alone and was losing her memories, through AD, she had also lost what Walrath refers to as her “internal governor” and shares her inner thoughts about her life that Walrath had never known (Walrath 11). While Alice may have lost her independence, she is still able to bond and connect with her family, in some
cases more so than before her illness now that she has less inhibition when talking with Walrath, helping them connect in new ways.

The second image is similar to how faces are portrayed in the final section of *Wrinkles* as Alice is shown in several panels, but always with parts of her body missing, showing that while AD patients can initially hide their symptoms, eventually they are unable to do so. In the image, Alice’s face is portrayed at the top of the page four times and each portrayal has something missing: her eye, nose, mouth, or hair. In the lower half of the page, Alice’s whole body is shown, but again she is missing something: one hand, both hands, one foot, and her face. The text spread over the first page reads “She isn’t losing tangible parts” and finishes at the bottom of the page with, “Though she is disappearing” (Walrath 16). Not every Alice presented in this image is easily identifiable as missing something with a quick glance, especially the full-bodied Alice images. The Alice missing her face entirely stands out completely, while the rest may take a more lingering look to find the missing part. The ability to recognize yourself is critical to selfhood and for both *Wrinkles* and *Aliceheimer’s*, the loss of the character’s face indicates a loss of selfhood. However, reading the connected narrative helps see a beneficial side effect to Alice losing her memory as she has also lost her inner-racism and now sees herself as beautiful, putting aside her “blond values” and instead embraces her heritage through her scarves and jewelry (Walrath 17). Viewing this image through the lens of hypertext shows Alice literally fragmenting in stages across the page, but never fully losing herself nor losing the ethereal qualities that Walrath has created for her. Alice remains recognizable throughout the text, even when she is struggling to differentiate delusions from reality.
Ultimately, though pieces of her may be disappearing, Alice’s physical form is still decidedly recognizable and present, regardless of the iteration presented here. It is also important to note that even as Alice is fragmenting and losing physical parts of herself, she remains in her otherworldly appearance rather than marking this as something to mourn. Walrath created new versions of her mother that celebrated her, even as the disease progressed. These vignette stories and images create a large gap that the reader must actively connect through the paper clothes of *Alice in Wonderland*, the hallucinations of pirates and deceased husbands, and the physical reality of Alice’s AD. *Aliceheimer’s* combats closure through these large gaps between images and text, the short vignettes, and a lack of linear narrative connecting them together. In *Aliceheimer’s*, Walrath found that treating AD as a superpower rather than a degenerative illness made connecting to her mother easier and increased Alice’s quality of life by acknowledging her hallucinations and delusions as unique stories and perceptions.

**Conclusion**

While AD patients themselves may struggle to write neurocomics, these works provide an outlet for carers to express their experiences with caring for an AD patient, often a loved one with AD. These works show the agony of this condition and the struggles and shifts in relationships that occur between themselves and the AD patient, often forcing the writer to create multiple versions of the AD patient as they continue to progress with their AD. The advantage of the comics medium is that authors are able to provide illustrations to show complicated emotions that would not be as powerful in word form. As Landow argues, one of the ways to examine works that pull from hypertextual elements is through the visual as hypertext has a “tendency to
marry the visual and the verbal,” making comics a unique medium to explore through the lens of hypertext (220). Calvi notes that hypertext and comic art aren’t often discussed and she argues that more research needs to be done to explore how the two may inform one another, particularly as she argues that the “contact point between comic art and hypertext is their resort to a pictorial narrativity” (135). The images in these AD neurocomics combat the stereotype that AD patients have no sense of selfhood immediately after diagnosis. Wrinkles shows that aspects of the patient’s personality like humor remain and that while the disease does ultimately reduce the AD patient’s ability to express themselves, their love and connections to others remains. Roca’s work also emphasizes the process of becoming a caregiver and the strong bonds that tie carer and patient together.

While Wrinkles doesn’t get into much detail about the caregiving process, Leavitt’s work emphasizes the struggles of caring for a loved one with AD and the conflicting desire to both preserve the memory of her mother and adapt her relationship with her mother to come to terms with her illness. Tangles uses white spaces to complicate the linear progression of the illness and Leavitt leaves the reader with an image of how she remembers her mother after her passing, smiling and surrounded by flowers, rather than with the image of her death. Both of these works focus on AD bodies as the reader watches the progression of illness, and in Leavitt’s case the death of her mother.

These works allow what DeFalco refers to as the “messiness” of caring, the frustration, sadness, and physical and mental deterioration of a loved one, alongside beautiful moments of memories and love between carer and patient (237). While Roca and Leavitt have these small moments of escapism, Walrath’s Aliceheimer’s tells the narrative through the fantasy of Alice in
Wonderland to help her see her mother’s AD symptoms as superpowers or otherworldly experiences, rather than a loss of herself. Through this focus on fantasy, it also serves as a means to normalize the caregiving process as a means of healing, even as they both prepare for Alice’s death. Neurocomics allow these dependent bodies to be seen, while still maintaining a sense of selfhood and identity. By exposing readers to the reality of caring for an AD patient, these works help normalize the need for dependency and also call into question previously conceived stereotypes and stigmas surrounding AD. These representations of AD are not textbook explanations, but examples of the reality of living with a loved one with AD and how this disease impacts both the patient and their families.

Using hypertext as a lens for reading these comics does show the fragmentation of self as the disease progresses and shows how these works require reader interaction to connect these fragments into a whole concept of the AD patient while traversing the complicated narrative structure. While the structure of Wrinkles is arguably the most linear, the narrative still branches off into the past of Emilio and the other residents, and the reader must utilize overheard dialogue, facial and body language, and previously discussed detail to fill the gap between panels and pages. Tangles utilizes panels as well, but the large white-spaced filled panels combat linear progression, and recenter the focus of the comic on Midge, even as Leavitt continues to drive the narrative. Tangles also utilizes space by providing panels to everyone in the family, giving them their own means of reacting and adapting to Midge’s AD, but also allowing Midge a space of her own within the panels, on equal terms as a family member. Aliceheimer’s defies any linear sense and relies on episodic narrative moments, not unlike AD patient’s memories towards the end of their illness. Walrath also utilizes the bend in the book, both added to reflect the pages of a
notebook and the actual physical structure of the book to both separate and connect the images to the text, requiring the reader to bridge the gap.

As Hernández Gonzalez argues that the range or combination of realistic and cartoonish drawings reflect the mental state of Karen in *My Favorite Thing is Monsters*, a similar argument can be made about these neurocomics. The drawings in these works all emphasize the fact that while there is loss and fragmentation of selfhood, through social bonds, the person is never nothing; their selfhood is carried by and survives through the memories of others (242). *Wrinkles* and *Aliceheimer’s* both show how relationships can be formed and mended through the act of caring and *Tangles* shows that Midge never completely forgot the love for her family, even as she was in the final stages, as she still had physical reactions to their presence. As Bolter argues, “hypertext refashions and revalues techniques of displacement,” so viewing these works through the lens of hypertext complicates the idea of these AD patients simply disappearing as their AD progresses (130). Neurocomics offer a way to confront our fears of aging, illness, and disability as well as normalizing the care and reliance on others. Reading neurocomics through the lens of hypertext offers new ways to explore how selfhood and illness are expressed in comic form. As comics become a more accepted medium for complicated and personal narratives, they provide a new means of addressing AD for the public and combat stereotypes while acknowledging the real loss that AD brings. While hypertextual elements are utilized within neurocomics through their images and organization, the final chapter will focus on neuromemoirs and how their use of hypertextual elements complicates their representations of Alzheimer’s Disease even within more traditional print mediums.
CHAPTER 3: FORGET ME NOT: NEUROMEMOIRS OF ALZHEIMER’S DISEASE

Introduction

While the previous chapters have focused on works that represent the experiences of an Alzheimer’s Disease (AD) patient by someone that does not have the disease, the works within this chapter are written by someone who is experiencing AD firsthand. As we rely on memories to help create a sense of our selfhood, many have questioned how memory loss due to injury or illness alters patients’ perceptions of self or if they lose any sense of selfhood. In *Living Autobiographically*, Paul Eakin argues that writing about our experiences or trying to encapsulate our thoughts and history, is not vanity, but rather “part of the fabric of our lived experience” and “narrative is not merely about self, but is rather in some profound way a constituent part of self” (Eakin 2). Eakin also notes that what we may consider selfhood is not only built upon our experiences of ourselves, but how we measure selfhood. In fact, Eakin notes that the ability to self-narrate is so common that it is often a measure of a healthy brain (47). However, this concept of normality is disrupted when the brain is injured or the person becomes ill and this raises questions about the duration of selfhood. This question of enduring selfhood is particularly complicated for progressive neurodegenerative illnesses such as Alzheimer’s Disease. Eakin argues that researchers have rightfully rejected the idea that the self is all or nothing, a concept that has been expressed towards patients with AD as he notes “some nonverbal, nonnarrative senses of self doubtless continue to function after extended selfhood has run its course” (Eakin 49). This argument suggests that while selfhood may not be expressed as
easily in AD patients, it does not mean that selfhood has entirely dissipated. Rita Charon in *Narrative Medicine*, she argues that “autobiography cannot be considered apart from fundamental beliefs about the self, which in turn are influenced by beliefs regarding the nature of language, thought, consciousness, time, memory, and relation” (70). Reading autobiographies or memoires written by AD patients further complicate this idea of enduring selfhood and provide a direct description from the patients themselves, rather than through a researcher.

For AD patients, memories are lost, and in the final stages of the illness, self-expression is extremely rare, so it is difficult to measure an AD patient’s sense of selfhood. We often have a preconceived idea of AD patients: older people lying on a bed, unable to communicate and slowly dying. Authors such as Susan Behuniak, note that descriptions such as zombies have been used to describe AD patients, slowly falling apart with a limited ability to communicate or connect to others. This idea of “zombification” is similar to Sack’s comment on patients without memories lacking “depth” and implies that the diagnosis of AD marks these people as somehow less than human (Sacks 112). However, a rising genre of autobiographies and memoirs written by AD patients have complicated this image of AD through the words of the patients themselves. Rather than viewing the diagnosis as a death sentence, these works provide the prospective from the AD patient themselves, rather than through the summation of doctors or researchers, and combat this stereotype that AD patients lose all sense of selfhood. These works are often written with a combination of different perspectives, scientific research, and several key events in both the author’s past and present, with the goal of expressing daily life with AD. These written accounts from AD patients are even more critical in regards to understanding selfhood due to their intrinsic focus on the patient’s sense of self and what shapes or influences that sense of
selfhood as they adapt to the progression of their illness. These autobiographies and memoirs provide direct description from the patients themselves which shows their “depth” and combats the stereotypical image of a zombie patient.

**Neuromemoirs**

The works in this chapter will be referred to as neuromemoirs, also referred to as brain memoirs, rather than autobiographies, due to their emphasis on the brain. Jason Tougaw argues in *The Elusive Brain* that neuromemoirs are a representation of the writer’s experiences but also an example of how they are responding to their altered brains (Tougaw 74). A more detailed definition of neuromemoirs with examples can be found in the Introduction chapter. Through neuromemoirs, the authors must directly address their understanding of self and how their own lives and their own identities fit into, but are not overshadowed by, their diagnosis of AD. While these neuromemoirs directly address their illness, they also provide details about their life and history before AD and what they hope for in their futures, making AD a part of their narrative, but not all-encompassing. This chapter will focus on the neuromemoirs *A Tattoo On My Brain* by Daniel Gibbs with Teresa Barker, *Memory’s Last Breath* by Gerda Saunders, and *Somebody I Used to Know* by Wendy Mitchell. These works complicate the understanding of identity and memory through their debates about selfhood. While there are many examples of neuromemoirs, for the scope of this paper, these three were chosen due to their ability to challenge societal biases regarding Alzheimer’s Disease through their complex narrative structures and rich discussions and accounts of living with AD. As Charon argues, selfhood is influenced by several different factors and likely changes as it is explored (4). These neuromemoirs explore the
concept of selfhood after their diagnosis through scientific research, but also through exploring their past experiences and social connections. These authors also acknowledge multiple versions of themselves as their symptoms waxed and waned and these selves are woven throughout the narrative creating a complex non-linear structures and providing a means for multiple voices to be included in their memoir.

Neuromemoirs provide unique narratives that aim to do more than recount a person’s experience. In Pramod K. Nayar’s work *Alzheimer’s Disease Memoirs*, Nayar argues that “the person survives in the AD body, in some residual form,” even in the later stages of the disease and that memoirs are a means of retaining the personhood of the AD patients (6). As this chapter will show, within these neuromemoirs, the authors to create a narrative that allows for their past, present, and future selves to exist within the same work, and often at the same time, through the author’s exploration of their selfhood, their social connections, and their agency. While the previous chapters discuss works that have clearer connections to hypertextual elements, reading these printed works through the lens of hypertext provides layers and connection points between the author’s sense of selves throughout their lives and how they imagine their futures. Though hypertext is often associated with digital works, reading printed text through the lens of hypertext provides a unique approach to the material, especially printed text that combines multiple forms of media, takes places over different periods over time, or includes multiple perspectives. Scott Rettberg in *Electronic Literature* argues, “The material aspects of electronic literature do not themselves determine the genre...because we can transcode from text strings, lines of code, into images, audio recordings, telephony, video, computational media cannot be understood as fixed” (Rettberg 7). David Bolter in *Writing Space* argues that hypertext can come
in a variety of forms and included printed text, though printed text has limited pathways of traversal compared to digital hypertexts (40-41). George Landow supports this claim in *Hypertext 3.0* and argues that applying hypertext as a lens may provide a new means of viewing works and revealing things that were unclear or not noticeable without the lens (219). This chapter will approach these neuromemoirs through the lens of hypertext as a means to understand the structure of works that don’t present as hypertext in form. As AD is a degenerative disease that causes fragmentation of memoirs, reading these works through the lens of hypertext show this process of fragmentation, but also emphasizes the connections between these key moments as the author’s re-examine themselves and their concepts of selfhood.

AD patients can write their neuromemoirs by themselves, or with some editing assistance, and they can explore their own definitions of selfhood and expand on their experiences through text and images. Tougaw claims that brain memoirs provide new means of narrative structure to describe the relationship between the brain and the mind or the complicated relationship between physiological processes and consciousness that remains heavily debated (75). Katherine Hayles noted the many hypertextual elements in Tom Phillips *A Humument*, including different styles of handwriting, images, and a collection of different materials within the same work which pushed back against a cohesive narrative, despite the fact that the physical materiality of the text creates a more traditional singular narrative (25-26). Making a similar argument to Hayles’ approach towards these three neuromemoirs is appropriate given that these works contain layers of narratives varying from jumps in time, different forms of media from images, brain scans, letters, or emails, and occasionally other voices from the author’s voice
speaking to themselves or another person’s writing or perspective. The authors expand the concept of a single self into multiple selves that make up their overall sense of self. As Nayar points out, the concept of AD patients making multiple selves is well discussed within the literature, but the unique narrative structure of neuromemoirs in creating and perpetuating these selves is underdiscussed. Neuromemoirs complicate stereotypes regarding AD and allow patients to regain a sense of agency by telling their experiences through this unique medium. These layers allow the authors to explore their sense of selfhood through different points of time and also enables multimodal composition to allow different types of text and images.

**Tattoo On My Brain Summary**

The first neuromemoir, Daniel Gibbs’ work *A Tattoo on my Brain: A Neurologist’s Personal Battle Against Alzheimer’s Disease*, is a prime example of utilizing multimodal elements to discuss selfhood. In this work, Gibbs describes how an unexpected result in his genetic test led him to discover that he had two copies of the APOE-4 gene, one the highest genetic risk factors for AD. While he notes that having a copy of the APOE-4 gene does not ensure that he would eventually develop AD, and some carriers of the gene never exhibit any symptoms, the presence of two copies of the gene caused him to analyze himself for possible hints of cognitive decline (Gibbs 50). Gibbs writes from a unique position; as a neurologist he had diagnosed and treated several patients for AD. At the time of the genetic test, Gibbs was 62 and already struggling “with recall of names and words,” but he was still able to teach and was still able to easily access information from his neurological background, making him “cognitively normal” (Gibbs 61). His diagnosis at 62 would be considered early on-set AD
Concerned that his cognitive decline would impact his patients, Gibbs chose to retire and to instead focus on his condition. Due to his background in scientific research, he argues that “it felt natural to turn that clinical gaze more fully” onto himself and become a “longitudinal study of one” (Gibbs 64). For Gibbs, using research was a coping mechanism for dealing with the diagnosis, and through the process of his research and active participation in clinical trials, he re-evaluated his concept of selfhood and memory.

Selfhood In A Tattoo On My Brain

Gibbs’ impetus to write this neuromemoir and participate in AD research to slow his cognitive decline come largely from his definition of selfhood. While he points out that neuroscience has multiple ways of defining and explaining the process of memory and how AD alters the brain, destroying the neuronal connections, for Gibbs, “in purely human terms, what’s at stake in memory loss is our fundamental sense of self: who we are, what we know and feel and believe, and how we belong and live in the world. Memory and memories create us. They define our self to ourselves and one another in the most profound ways…” (Gibbs 221). The focus on “human terms” is particularly telling here; while speaking in scientific terminology, there is a separation between the mechanisms in the brain and the actual person experiencing these changes. This is the core of narrative medicine: restoring the patient as the focal point rather than a number or case study (Charon vii). For Gibbs, memory provides critical grounding and impactful pieces of information that inform a person who they are and how they are connected to others, making them the foundation of selfhood. To lose these memories to AD, is to lose all sense of selfhood.
Understanding Gibbs’ definition of selfhood is critical to this work as it provides the basis for this project and the drive to inform the public on the realities and treatments for AD. He states, that “When we talk about buying time with earlier diagnosis and treatment, that’s [selfhood] what we’re talking about. There’s no time to lose” (Gibbs 221). Gibbs addresses Eakin’s ideas of selfhood here as he clearly connects his sense of self to his memories, yet also acknowledges that a diagnosis of AD does not automatically remove all semblance of selfhood. Though Gibbs relies on memory tools like note taking, mnemonics, and organizers, he emphasizes that AD is not the center of his life (Gibbs 188-189). Rather than “obsessively waiting for some new symptom,” he keeps track of his scores, notes changes in his cognition, but he does not compare scores between his visits with his doctor (Gibbs 189-190). However, while Eakin argues that selfhood remains during the later part of the disease, Gibbs’ definition of selfhood relies on the interconnections of memories to create a sense of self, so the fragmentation of memories associated with AD, would result in a loss of selfhood.

While Gibbs raises concerns about his sense of selfhood ending with the fragmentation of his memories, reading this neuromemoir through the lens of hypertext emphasizes the network of selves, rather than a singular self in Gibbs’ neuromemoir. Gibbs creates a duality of self through his neurological research. The inclusion of research provides more than just a record of Gibbs’ research into AD, but also proves a means to understanding his thought process as he is a neurologist. Gary Johnson argues that neuronovels, fictional works that focus on the brain, brain illness, or consciousness, often interrupt their narrative to include a brief educational moment, especially when the character has a neurological condition, to inform the reader about the condition before continuing with the plot (174). However, reading this work through the lens of
hypertext allows the reader to see these chapters that emphasize scientific articles or research as both separate from and part of Gibbs’ sense of selfhood as he both tries to educate the reader through this multimodal approach, yet also explains how this information has informed his sense of selfhood. These sections are often interspersed with his own personal experiences, first when he was diagnosing his own patients and then later as he begins to notice symptoms within himself, intertwining Gibbs’ past experiences with patients with those he experiences as well.

Gibbs’ participation in a clinical trial for AD highlights his duality as a neurologist and now as a patient. When Gibbs joined the researchers to review his own brain scans, he noted the strangeness of being on “the patient’s side of the table” and to sit with colleagues “gathered to talk about my brain, my cognition, my diagnosis” (Gibbs 83). This is the first and one of the most important segregation of selves for Gibbs as he has previous experience diagnosing AD patients and now he must apply this information back to himself as a patient. This moment also provides another critical multimodal piece of information in Gibbs’ own brain scan. As described in Chapter 2, Jason Tougaw notes that brain scans provide another way to view and understand the brain, but these images can lose touch with the personhood of the patient (226). In Gibbs’ work, this personhood is on clear display through Gibbs’ sense of selves.

As Hayles notes, print or electronic hypertext pull on the materiality of their mediums, and while Gibbs’ work is not a hypertext, viewing the structure through the lens of hypertext complicates Gibbs’ sense of selfhood in this scene (22). Gibbs’ brain scans take up two entire pages with a brief description under each image. This description is critical to the image, not just to educate the reader on what the image is showing, but also to allow Gibbs’ ownership of the scans as he referred to each scan as either “my amyloid PET scan” or “my imaging,” providing a
means to connect these images to his sense of self. The narrative text frames these two images, which separate them from the narrative, but these descriptions prevent them from existing outside of the narrative at the same time. Gibbs undergoes a similar connection and disconnection at the same time as he notes that the scans “were, just objectively speaking, beautiful in the way brain scans are…” and that they also contained “the unmistakable signs of Alzheimer’s” (Gibbs 83-84). He also oscillates between his training as a neurologist in examining the brain and as the owner of the brain, impacted by these plaques and tangles and already expressing symptoms of the progressive disease. In this neuromemoir, the reader is physically holding a copy of these scans, representing the inside of Gibbs’ brain and the physical reality of AD, while also able to read his narration of the events and his feelings during and after this meeting. Unlike the interruption Johnson argues happens in neuronovels, this incorporation of images and the splitting of Gibbs’ sense of self provides a more in-depth understanding of Gibbs’ selfhood.

As Gibbs progresses in his disease, he also echoes Behuniak’s note about the fear of reducing to a zombie-like state through AD. Gibbs notes that AD discussions tend to “fast forward” to the end while ignoring the time the patient has, so he emphasizes early diagnosis and treatment, but also suggests that the patient slow down and appreciate their remaining time (Gibbs 9). Time remains a major theme as Gibbs pushes for the importance of early diagnosis and he argues that the focus on AD as a whole needs to shift from the stigma and fear of the end stages to acknowledge that the AD patient may have plenty of years of relative cognitive normality before the end stages (Gibbs 9). He notes the case of his patient who took their own life directly after their diagnosis, and while this discussion happens much later in the work, it
clearly connects back to Gibbs’ overall impetus for writing this work, stressing that the stigmas of AD take away years from patients (Gibbs 157). His sense of agency will be discussed in more detail in later, but this fear of becoming like a zombie does not pervade his sense of self, but instead drives him to continue with his life with as much normalcy as possible.

Social Connections In A Tattoo On My Brain

Though the neuromemoir focuses on Gibbs’ experiences, by viewing this work through the lens of hypertext, the network of social connections and their impact on both Gibbs’ AD and his definition of selfhood become clearer. Landow notes that hypertextual works are often structured to avoid hierarchy and instead focus on networks and applying this concept to Gibbs’ work allows these social connections to become clear (1). While Gibbs fears his fragmenting memories will result in his sense of self, the social connections he has in his wife, family, and friends help him retain his memories and sense of self. Initially, Gibbs was hesitant to ask clarifying questions to his wife Lois, because he didn’t want to show his impairment and concern his wife (Gibbs 71). After speaking together, Lois began to point out any memory lapses to help Gibbs focus, but also helped him become more comfortable confiding in her and even laugh about his slips (71). His relationship with Lois broadens Gibbs’ definition of selfhood as constrained to the network of memories to include the networks within his social relationships.

Similarly to how Gibbs breaks up his sense of selves, viewing his connections to others as a network connecting to his sense of selfhood reveals the broad impact of Gibbs’ AD. Gibbs states, “I call it “my” Alzheimer’s disease, and of course, the pathology is in my brain alone. I’m also entitled to ownership of the disturbing feeling that this might be “my” new life, that these
were “my” problems, “my” frustrations and “my” fears,” but he also acknowledges that his condition impacts his entire family (Gibbs 110). While the neuromemoir focuses on Gibbs’ experiences thus far in his condition, he freely acknowledges that he will not be the only one impacted. He notes that his participation in clinical trials is related to his hope that the results may provide treatment for his children, who also carry the AD gene, but tries to limit discussing the negative side effects of his AD with his children unless there is a major change (Gibbs 119, 192). As Gibbs is in the early stages of AD, he only needs minor assistance from his wife, but as his disease progresses, he acknowledges that his children may begin to play a larger role in his caretaking (Gibbs 192). His neuromemoir opens with a picture of his children as part of his acknowledgments, also emphasizing his connections with his family, even before getting into the text of his work.

Viewing Gibbs’ social connections as a network related to selfhood also helps de-center AD as the focus of this neuromemoir, and rather than fixate on his fragmenting memories, instead emphasize his personhood. The text intertwines Gibbs’ past with his experiences with AD and he utilizes photographs of specific places, such as Beacon Rock, and of family members and friends that are particularly important to him. Hayles notes that the images and text in A Humument provides a dual representation of the outside world and Toge’s interior mind (29). This is reversed in Gibbs’ work as the majority of the text is Gibbs’ thoughts, but these images provide physical places and his friends and family, breaking the interior focus and connecting Gibbs back to his social network, disrupting the focus on Gibbs’ AD. While it is important to note that Gibbs does occasionally connect these moments to AD and also includes scientific research on AD that also breaks his personal narrative, the inclusion of these images and
descriptions of his relationships to others shifts the emphasis to Gibbs as a person experiencing AD, rather than a clinical description of an AD patient.

Agency In A Tattoo On My Brain

Many people feel helpless after getting a diagnosis with AD, but writing down their reactions and research has been shown to help many patients regain a sense of agency and writing has been shown to help retain cognitive function (Beard 418). While Gibbs acknowledges that he is not familiar with writing outside of medical and scientific research, ultimately what prompted Gibbs to write was a sense of urgency as he was not sure how long he would be able to write (Gibbs 181). Dick Swaab in *We Are Our Brains* claims that maintaining language skills is common in AD patients until they reach the final stage, Stage Seven, when these areas of the brain are impacted by the disease (347-348). Creativity and music skills are often preserved far into the progression of the illness as well and Swaab notes that some musicians were able to play instruments with musicality in the later stages of their AD (348). Another important aspect of AD is the “use it or lose it” mentality. As with all progressive illnesses, the loss of function will only continue to grow worse over time. Gibbs mentions that writing this neuromemoir with AD was very difficult, both in terms of writing for any length of time without losing his train of thought or getting stuck on words (Gibbs 224). He also noted that if he had an idea, he had to immediately write it down regardless of what activity he was doing in order to retain the thought (Gibbs 224-225). Despite the difficulties, this work is also not entirely scientific either, as he incorporates important personal memories alongside his research on AD and his difficulties with the illness.
However, rather than viewing the scientific sections as interruptive of the narrative, they may be read as mimesis, or Gibbs’ representation of his thought process. As described in previous chapters, applying Bush’s memex, an early version of hypertext that organizes information through association and has been linked as a possible model for the human thought process, to these works provides a new means to explore these neuromemoirs. By reading this neuromemoir through the lens of hypertext, the inclusion of these experiences, research, and philosophical discussions can intermingle to create a greater understanding of Gibbs’ thought process and life experiences. Gibbs’ narrative weaves in and out of memories such as telling his diagnosis story, medical/clinical events, previous work experiences, with more scientific references and his own photographs. Relating Gibbs’ work back to Bush is also apt as Bush noted that structures like the memex would not “fade” due to forgetfulness or time. By creating this neuromemoir, Gibbs has provided printed collection of his sense of selfhood, something that will remain even when the memory of writing it will have faded. To structure the narrative, Gibbs utilizes key moments in his life with specific dates to help the reader keep track of the progression of his disease within the narrative while regularly jumping backwards in time to focus on family memories or other important moments in his life. Some of these memories are directly related to his disease, while others provide more background information on how he grew up and what he values as a person. These regular shifts between the narrative and scientific research create two interconnected structures within his neuromemoir as he seeks to educate the reader about the disease, but also clearly notes that this scientific approach is comfortable to him as that has been his career and area of research. Rather than reading this as an interruption,
viewing this neuromemoir through the lens of a hypertext provides a way of viewing Gibbs’ thought process.

While this neuromemoir does encapsulate specific memories and experiences both before and after Gibbs’ diagnosis, it serves another function as well, to reach out and directly combat the stigmas associated with AD. Gibbs’ stated goal for this work is to combat AD’s “power to avert our gaze, to muzzle the potential of science and medicine to make more dramatic strides, to intimidate and silence us and, in doing so, have us fail to address the challenges and promise that early diagnosis and treatment may hold” (Gibbs 181-182). All the authors in this chapter found that when they went public with their diagnosis, they immediately noticed a change in the way their neighbors and friends interacted with them. There is a prevalent fear of AD and the stigmas around the disease only further drive individuals to view AD in fear. Ryan, Bannister, and Anas focus on the writing as a means of regaining a sense of agency and identity in AD patients. The authors argue that writing allows for a patient and non-judgmental place where AD patients can take their time and find the proper words and sentence structure they need without the need for speed or feelings of embarrassment for hesitations in conversation (Ryan, Bannister, and Anas 156). Gibbs’ work can be seen as a call to action for AD patients with the goal of getting earlier diagnoses and earlier access to treatment and awareness of lifestyle changes that can slow the progression.

*Tattoo on My Brain* provides a unique insight to Gibbs’ experiences with AD, but also his sense of self is impacted through his own understanding of neuroscience, his memories, his social connections, and his sense of agency. While the work describes Gibbs’ understanding of his AD, it does not lose sight of his personhood beyond his illness. The inclusion of multimodal
elements and multilinearity in the narrative directly connect his experiences to others and shows the impact of AD beyond the AD patient. Reading this text through the lens of hypertext complicates the concept of fragmentation in AD through the connections of his senses of self and through his connections with his friends and family.

**Memory’s Last Breath Summary**

Similarly to Gibbs’ combination of science and personal experience, in *Memory’s Last Breath* by Gerda Saunders, the author recounts her experiences with AD in the form of “field notes” in her secondary title. Unlike Gibbs, Saunders did not find out her diagnosis through a genetic test, but went in for testing after several instances of memory lapses. These moments of lost time or forgetting specific memories were especially concerning to Saunders as her mother suffered from something similar, though she was never diagnosed (Saunders 7). Her descriptions of her cognitive decline are overall disparaging referring to it as “decline,” “unhinging,” or “deficits” (Saunders 7-8). Her word choices are particularly interesting as she is an English PhD and uses literary references to characters such as Don Quixote and Jane Eyre to help her understand her illness. She grew particularly interested in the term dementia which can also be a verb as she states, “I am dementing” multiple times in the neuromemoir (Saunders 9). As with Gibbs, Saunders pulls from neurological research to understand her disease and found that medical treatments for AD were limited and the treatments that do exist can only slow, not prevent the decline (Saunders 8). For Saunders, she notes an immediate change after learning about her diagnosis, stating that “the separate circles in which I had kept the images of myself as a woman who lives and dies by her rationality and that of my mother after her illness as a
Dickensian madwoman gradually began to overlap like the intersection of a Venn diagram” (Saunders 13). Saunders slowly started to accept her diagnosis and the reality that her brain is deteriorating, but that the illness did not equate to a loss of selfhood.

**Selfhood In Memory’s Last Breath**

Unlike Gibbs, who focuses more on memory and brain function as a form of selfhood, Saunders divides herself into multiple “selves” throughout the neuromemoir. Saunders chose writing as a means of expression “for selfish reasons” claiming that writing was “accessible” and through writing she was able “to flesh out my shrinking self with former selves” (Saunders 44). As described in previous chapters, expanding on Lindsay Starck’s stereoscopic to a kaleidoscope provides a new way to approach these fragmenting selves in neuromemoirs. As AD patients experience progressive neurodegeneration, applying Starck’s argument helps provide a means of combining and keeping these senses of selves apart. However, unlike Starck’s dual selves, AD patients have many selves, so perhaps a kaleidoscope is more appropriate than a stereoscopic as the patient’s cognition is altered with every version of self either due to age or progression of the AD, but all still belonging to the same individual and, at least in the early stages of AD, still able to retain some awareness of the other versions of themselves.

For Saunders, these selves appear and are often marked by specific timeframes or a major change. For example, one of Saunders’ earliest markers of selfhood is her intelligence. She cites a family story that she was able to go up to the store clerk and order bread when she was only two. She explains that “this and other similar stories, more familiar from their frequent retellings than my actual memories of the experiences themselves, formed the kernel of my “self” during
my formative years” (Saunders 75). This understanding of self is critical as it shows that selfhood isn’t necessarily created solely by the person, but also through their interactions with others and through the retelling of those interactions to establish a history which leads to a new “self.” Saunders states that she “mercifully gave up the notion that a strong intellect in my case…should constitute the core of any respectable identity” because intellect can be lost due to damage to the brain from an accident, showing her sense of selfhood is still changing (Saunders 75). While she may not view her intelligence as a core aspect of her selfhood, she still acknowledges her ability to rationalize and research is still very much part of her identity and it was this desire to know is what prompted her research into AD and writing this work (Saunders 75).

Starck’s multiple selves approach also helps complicate Saunders’ sense of selfhood through the inclusion of several of Saunders’ journal entries. Saunders was able to incorporate other forms of writing into her work including journal entries from before and after her diagnosis. In one section, Saunders gets lost in a Macy’s store and was locked in an emergency-only stairwell. She was forced to call her husband, who got security to let her out and gave her water until her husband arrived. Yet, two pages later, she quotes from the Bible, Don Quixote, and Jane Austin and references a childhood memory to discuss vanity. These entries are useful as they juxtapose Saunders’ difficulty with seemingly basic tasks compared to her obvious intelligence and expansive education, complicating both the stereotype that the progression of AD all-encompassing and showing her oscillating impairment, but remaining intelligence and memory. Her intelligence is also shown in the inclusion of her research into AD, including some images of rats, brains, and brain diagrams. Viewing these multimodal entries in Saunders’ works
creates the added depth to Saunders’ selfhood that Starck describes, only through a more diverse collections of selves rather than the dual combination of past and present self. These multimodal elements show how she may have difficulty with basic tasks, but her intelligence and education are still available for her. Ryan, Bannister, and Anas argue that writing is a way to show AD patients their own growth and learning, something that is regularly considered impossible after a diagnosis of AD (156). Not only does this allow the AD patient a space to reflect and come to terms with the changes in their lives, but their social interaction with others, even if they only interact through writing, has shown to be a way to preserve AD patients’ sense of self (Ryan, Bannister, and Anas 156). As with Gibbs, keeping a diary provides a printed version of selfhood and a means of recording Saunders’ discussion of selfhood, even as her memory of these events fade over time.

Saunders’ in-depth discussion of selfhood further complicates the concept of fragmentation due to the neurodegeneration within the early stages of AD. Similarly to how Gibbs used his neurology background to define his sense of selfhood, Saunders continues to attribute her research and her education for her understanding of selfhood. She notes that “For those of us acculturated to the Western perception of personhood, the unspoken assumption behind this question [Who am I?] is that we have “a kernel of identity, a self,” for example, the self we are encouraged “to get in touch with” or “be true to”” (Saunders 224). This emphasis on the individual is important in Western culture compared to other cultures that focus on the collective wellbeing. However, she argues that she doesn’t believe in a singular self, in the sense that a person has a completed and fully formed self at any given time, and instead pulls from her Freudian and postmodernist education to argue that there are many forms of self and that looking
for the self only further divides the self (Saunders 224). She also pulls from Lacan, religious
texts, the impact of nationality and culture, and cosmic scientists, comparing their understanding
of self to come to her own conclusion (Saunders 224-227). She argues, that “the postmodernist
self resonates with the way I experience myself. I am never done; aways changing…” (Saunders
227). Altering Starck’s stereoscopic to a kaleidoscope instead is an effective way to view
Saunders’ sense of selfhood as she views selfhood as an interconnected and ever-changing
concept rather than a singular hierarchical self. While the social connections will be discussed in
more detail in the next section, Saunders’ sense of selfhood shifts, so combining multiple selves
that are impacted by many different factors, including her AD, complicates Starck’s dual past
and present self. Saunders’ understanding of self connects to her previous argument about why
she wanted to write this neuromemoir: to find a place to connect her previous selves together as
she feels her own sense of self and her capacity to think about her selfhood start to fade. This
sense of selfhood also serves her well in the sense of her progressive illness: selfhood is always
changing and in this case, her sense of selfhood is primarily responding to her illness, but this
does not erase her previous selves and her connection to these selves help keep her sense of
selfhood. Through the lens of hypertext, the readers can see the fragmentation of these selves
while also still viewing the connections from Saunders’ current self to her past selves.

Social Connections In Memory’s Last Breath

Saunders’ work supports Nayar’s concept of network and interconnections as a means of
identifying selfhood. Saunders’ inclusion of multiple voices within her narrative through her
mother’s journals and memoir entries, siblings and family members’ emails, and her own
research and specific entries from her journal provide multimodal elements that emphasize these connections. Images of family members, sections from the journal, and notes about neuroscience are interspersed throughout the narrative. Her flashbacks, in particular specific memories of her childhood, don’t initially connect to the narrative; however, they are connected or referenced directly later. Bolter argues that “memory is not univocal” and providing multiple narrative pathways can provide a “means of capturing the authentic multiplicity of memory” (127). Stories such as killing the puff adder later connect to the debate about “truly” remembering an event when memories are rarely exact replicas and she uses the emails from her family members to show that her basic facts were correct, but there were slight variations between her family members’ accounts. Initially, the reader may be confused why these stories are particularly relevant and these vignettes can stand alone as a fragmented story; however, after noting the similarities to hypertext in the multimodal structure and the combination of outside perspectives, the benefit of including these references is seen in her connections between this particular incident and how she her concept of selfhood as an interconnected network between others and that directly impact her continual development of selfhood.

While these emails focus on one specific memory, the inclusion of Saunders’ mother’s journals and memoir entries further stress Saunders’ argument on the impact of social networks on her sense of selfhood. As Saunders’ mother also struggled with a form of dementia that was never diagnosed, Saunders now views these texts very differently. Throughout the text, Saunders connects her mother’s memory issues and her difficulties in the later part of her life and worries that she will have the same problems. Reading this neuromemoir through the lens of hypertext, this collection of journal or memoir entries that are only notated with the title and change of font
to separate them from the rest of the narrative, show Saunders reconnecting and understanding her mother through her writings as she also navigates her life with her diagnosis of dementia. Like Hayle’s argument on Phillips *A Humument*, the inclusion and discussion of Saunder’s mother’s texts adds another layer of narrative within the work (Hayles 24). These not quite parallel stories allow Saunders to see her mother as she remembered her, but also to acknowledge the aspects of her mother as an adult beyond her role as her mother. Eakin states that while many readers may view autobiographies as the end of someone’s life, they have more stories to tell and the very act of remembering and mapping out our lives “helps us keep track of who we are” (170). Saunders’ exploration of her relationship with her mother, especially in light of her AD diagnosis, continues to combat the stereotype of AD patients cannot grow or change after their diagnosis.

One of the core structures of hypertext is “a shift away from linear storytelling towards a multi-threaded approach,” and reading this neuromemoir through the lens of hypertext shows that not only does Saunders’ complicate her sense of selfhood through her network of family relationships, but is also impacted by her friends and neighbors (Rettberg 57). Alongside her mother’s writings and her narrative are the struggles of Saunders’ neighbors Bob and Diane. As Bob is living with AD, Saunders watches as Bob becomes more dependent on Diane whose health problems raise growing concerns for Bob’s wellbeing and care in the long term. Updates on Bob’s health are interspersed through the narrative, creating another, albeit smaller, narrative that provides insight into Saunders’ feelings regarding her future and the importance of making decisions now with her loved ones. As Bob’s AD is more advanced than Saunders’ AD, these episodes show Saunders, and the reader, the difficult choices and burdens spouses must take up.
to provide care for their AD partners. The complicated structure of the neuromemoir allows space for Saunders’ mother’s experiences written in her own words alongside Saunders’ memories of her and how reviewing her mother’s writing has changed how she views her mother, especially in light of her diagnosis. The experiences of her neighbors are also transformed through these narratives, as Saunders’ now sees Bob’s experiences as her future. Saunders’ concept of selfhood is only further complicated through these social relationships.

Agency In Memory’s Last Breath

Saunders clearly connects her sense of agency to her identity. For example, the ability to choose her own clothing is something that Saunders takes pride in, but she began to struggle remembering the combinations of clothing she would use or the order of putting on pieces of clothing. As she considers her clothing as a means of expressing herself, she created photo albums to help her connect the right pieces of clothing and to get dressed in the correct order, rather than relying on others to help her get dressed. Her concern about losing her ability to get dressed connects to fears about becoming a zombie, a term she took from Jonathan Franzen who used this term to describe his father before he died of AD (Saunders 229). Behuniak argues that to combat this stigmatization, we need to view AD as a social problem that impacts everyone, rather than an unlucky few, to combat the isolation so often connected to AD and provide a more supportive network for patients (88). Saunders also supports this goal. She pulls from McKim Marriot’s term in “dividual” which focuses the “deep connection among single persons and their community” (Saunders 226). She claims that “I cling to my dividuality (sic) for self-ish reasons” as those with complex social connections and community are less likely to be as
heavily impaired by dementia (Saunders 228). By focusing on her connections to others, 
Saunders is able to slow her progression of her illness and have a larger community for support, 
but these connections also allow her relationships to help support her sense of selfhood as well. 
For Saunders, combatting the zombification of herself due to AD is not only preserving her 
individuality, but also her connections to others.

Another part of Saunders’ agency comes from planning her remaining life and her 
eventual death. Similarly to her inclusion of neuroscience research, Saunders includes 
multimodal sources to research and explain the options for AD patients to end their lives. 
Saunders and her family creates a “death plan” to travel abroad to Switzerland where assisted 
suicide is legal (Saunders 242). The trip is needed as the Death With Dignity Act in the United 
States is difficult to use with dementia patients as it requires a “sound mind” and there is an 
ongoing debate on whether or not AD patients are deemed able to make the decision on their 
own (Saunders 238). Saunders also considers using another method: Voluntarily Stopping Eating 
and Drinking (VSED) which is legal in the United States and refers to carers allowing AD 
patients to stop eating and drinking, providing them pain medication as needed, and giving them 
access to medical care if they request it, but with the sole purpose of letting the AD patient pass 
naturally (Saunders 243). Applying Hayles’ argument on how the images and text in A 
Humument provides a dual representation of the outside world and characters’ interior minds to 
this discussion breaks the reader from the narrative to connect them to the outside influences of 
laws that impact AD patient’s decisions (29). While there are no images in this discussion of the 
text, there are a collection of end notes that provide sources for her references, and the inclusion 
of the current laws provides another means of viewing agency, besides the daily choices, to
determining how the AD patient wants to live towards the end of their lives. Though Saunders acknowledges that it may be several years before she enacts either her death trip or VSED, having a plan helped her family understand her wishes and have a clear plan of action.

Saunders’ Memory’s Last Breath embraces multimodality and multilinearity to express her sense of selfhood as ever changing and irrevocably interwoven with her social connections of her friends and family. While Saunders fragments herself into several versions of selves, rather than viewing this process as a linear degeneration of self, these selves remain interconnected and combat the stereotypical loss of selfhood in the early stages of AD. By including multiple narratives within her neuromemoir, Saunders clearly represents her understanding of self through the network of connections between her various selves and her friends and family. Reading this neuromemoir through the lens of hypertext emphasizes the importance of these connections and reveals these networks in relationship to Saunders’ definition of selfhood.

**Somebody I Used To Know Summary**

Networks are also critical in Wendy Mitchell’s Somebody I Used to Know. Mitchell is a well-known advocate for AD patients and runs a blog named “Which Me Am I Today?” that she continues to regularly update. Her most recent work What I Wish People Knew About Alzheimer’s Disease (published in 2022) focuses on a combination of neurological research and personal experiences with the aim of helping patients with AD diagnoses, family members of an AD patient, or AD patient carers. This chapter focuses on her work Somebody I Used To Know as this neuromemoir describes her initial diagnosis and how she came to terms with her illness. Her diagnosis of AD was less straightforward compared to the other authors in this chapter as
she was initially diagnosed with having a stroke and the memory issues were associated with the stroke rather than dementia. While Mitchell does not come from an academic background, she has a unique position as being employed within the health care system. Mitchell’s initial memory slips were associated with stress at work and the discovery of a stroke. However, these memory lapses were particularly concerning as her strong memory skills were something that she not only took pride in, but considered part of her identity. Her job was very cognitively stimulating as she organized and scheduled the nursing shifts and her colleagues gave her the nickname “the guru” due to her strong memory and recall skills (Mitchell 7). As time passed, she also noticed other symptoms including slurring her words, muscle weakness, and fatigue alongside the “sensation of a head half-filled with cotton wool had continued for months” (Mitchell 10). As a single mother, Mitchell immediately worried about the impact of this illness will have on her two daughters and how she herself will cope with losing her independence. To regain a sense of agency, she became active in AD research through organizations such as the Alzheimer's Society and remained determine to live as independently as possible.

**Selfhood In Somebody I Used To Know**

As with Saunders, Mitchell fears losing her independence and becoming dependent on her daughters. She describes her three main fears as: losing her independence, “going over the edge into someone I don’t recognize, losing a grip on what makes me me,” and forgetting the faces of her daughters (Mitchell 71-72). Initially she tries to fight the diagnosis, by trying to perform what was normally a simple task for herself: putting up wallpaper to redecorate her home office, but after three failed attempts, she had to admit that she was unable to complete the
task (Mitchell 34). Unlike Gibbs and Saunders who retired shortly after their diagnosis, Mitchell wanted to stay at her job, but she was told to take an early retirement instead. On her last day Mitchell describes feeling, “…numb inside, let down by a system that isn’t willing to support people with dementia to stay at work, that can’t adapt and change like those of us living with it do” (Mitchell 132). This moment is critical to Mitchell’s work as she argues that society doesn’t make the needed effort to work with AD patients and this only adds to the stigma of AD.

Mitchell must fight the stigmas of AD to feel any hope for her future. When she is first diagnosed, the first thing that comes to her mind is “white haired, old people in beds, unable to recognize their own children, or to remember their own names” (Mitchell 22). A few weeks later, these vague images become replaced her with herself as she imagines her future stuck in a bed herself relying on her daughters’ care and preventing them from moving forward with their lives (Mitchell 47). Mitchell is unique in her approach to address these stigmas. Unlike the other authors who used traditional means of research (research papers and medical books), Mitchell went to YouTube to find firsthand accounts of living with AD. While she found images that matched her fears, she also found Keith Oliver. His interview changed everything for Mitchell as Keith Oliver also had early onset AD and looked just like Mitchell in terms of age and cognitive ability (Mitchell 41). This inclusion of Oliver’s video does show some limitations of the print medium as Mitchell cannot include a hyperlink or example of the video within the text; however, the inclusion of this video emphasizes the importance of first-hand accounts of illness. Mitchell was particularly drawn to Oliver because he looked like her and had similar experiences with AD, combatting the stereotypical images and progression of illness that Mitchell had been seeing. Despite this respite in her anxiety, with her official diagnosis, she states, “nothing
prepares you for a diagnosis of your own, for the feeling of emptiness, because I know those words, this letter, will change everything, they’ll change the life I know. They’ll steal the life I know” (Mitchell 46). The metaphor with AD as a thief is one Mitchell uses several times throughout her work. She constantly works to outwit or outmaneuver AD like it is her enemy (Mitchell 62).

Defining her sense of self is difficult for Mitchell as she regularly separates herself into multiple selves. Applying the kaleidoscope variation to Starck’s stereoscope argument helps connect these selves together, while still keeping them separate. The neuromemoir is full of letters to her past self, comparing these selves. She notes that people claim that she hasn’t changed at all, but Mitchell argues that they don’t acknowledge what she has lost to adapt to the changes in her brain (Mitchell 222). When she writes to herself, there is no clear indication that she is writing to her past self as there is no salutation, just a shift in text to italics. These letters are a mix of fondness and sadness, with clear admiration for her past self. Still, in one of her early letters in the neuromemoir, Mitchell notes similarities between the two selves noting, “…You liked a challenge, especially if it provided others wrong who thought you would never cope. Maybe that’s something we still have in common, and that gives me some comfort, that we still have some likenesses” (Mitchell 13). However, these selves don’t always come together smoothly. Mitchell claims that “… there are other times when the difference between the old me and the new me hits me so hard it leaves me without breath” (Mitchell 223). This moment is particularly important as it shows Mitchell’s awareness of these selves.

She gives the example of this recognition of the selves when she was using WhatsApp with friend and chatting normally, but then struggled to switch over to take a FaceTime call with
her daughter Sarah. She noted that when she tried to speak, it came out as a stammer and “almost childlike” (Mitchell 223). Her daughter quickly ended the call, but as Mitchell reviewed her conversations on the app compared to her daughter’s FaceTime call, she saw “the old Wendy, the one I knew for fifty-eight years. But this one, she is an intruder. I am not used to the two versions of myself crossing paths, but it had felt that, for a split second, they had met each other” (Mitchell 223). This moment is unique between the three neuromemoirs, as all three describes multiple senses of selves and awareness of the selves, but Mitchell is the only one to describe the two selves as meeting one another. As her disease progresses, the self who struggles with cognition and memory has become the more common self, compared to what Michell must now acknowledge is her old self. Reading this work through the lens of hypertext keeps these selves in conversation with each other, even when the author does not explicitly do so. The reader is privy to all of these selves at once and can note the similarities and differences as each one is described.

Similarly to Saunders, Mitchell also feels that she has multiple selves, though she initially breaks them up into pre and post diagnosis, she acknowledges that there were be more selves appearing as the disease progresses. She states, “I’m a different me today from the one I was six months ago. A different one from the one I was a year ago. I’m losing my sense of self, and that is more frightening than anything, because that’s all I have — that’s all any of us have. The one we call “me.”” (Mitchell 235). While she can function and remain independent now, Mitchell acknowledges that she is afraid of the future and if she can make decisions about how she wants to live her life and her plans for the end of her life (Mitchell 235). Like Gibbs, Mitchell associates her sense of selfhood in relation to her memories, so as the disease continues to “steal”
from her, she argues that there are “…some days it feels like there is little of me left” (Mitchell 224). She describes seeing a video of herself and not recognize the woman being interviewed (Mitchell 245). She understood that it was herself on the screen, but the way she spoke, and her mannerisms didn’t match with Mitchell’s understanding of herself. Instead, Mitchell feels, “the me I knew for fifty-eight years has already departed. I keep her alive when I can — in a funny blog post, or a WhatsApp message, an email or a quip written into one of my speeches. Is that the real me trapped inside— or is it the one who speaks on the outside? Is one of them a fraud?” (Mitchell 245). Though she does not include the multimodality of these examples, these selves have all been recorded in a form of text or video, that when placed together, show the many forms of Michell’s selfhood. However, these selves have varying levels of cognitional decline as the AD symptoms can wax and wane, so it is not surprising that Mitchell feels like her true self is trapped under the disease.

Through these recorded examples of her various selves, she creates a variation of Bolter’s argument that multiple pathways can present a better or “authentic” sense of memory (127). While Saunders pulled from her family members to check her memories, Mitchell pulled from these recordings of herself, using herself as a means of positioning her sense of self and her cognition from these previous selves. She mentions several times that she cannot trust her own senses due to the disease, so her ability to feel like she is actually herself is also compromised. Rather than viewing Mitchell as an unreliable narrative for this issue, reading this work through the lens of hypertext shows these selves in conversation with each other, waxing and waning in cognition as Mitchell’s AD progresses, but always connecting back to Mitchell in her desire to remain independent for as long as possible.
Social Connections In Somebody I Used To Know

This drive for independence makes Mitchell’s social connections particularly important to this narrative as she must re-establish her role within her family. When she is diagnosed with AD, her first concern is for her daughters and she is adamant that they will not become her carers (Mitchell 59). As they go over her wishes for how she will be treated towards the later stages of her illness, it becomes clear how much more complicated her life will be and how her daughters must balance Mitchell’s independence and her growing needs for assistance. This is seen in how the health professionals originally treat Mitchell when she joins an AD clinical trial. They initially direct their comments and directions to Mitchell’s daughter Sarah, thinking that she was Mitchell’s carer, rather than to Mitchell herself. Nayar notes that “The separateness of the person with AD from the social order is visibly marked, and this, while generative of a certain kind of selfhood in terms of its sheer divergence from the norm, is a discreditable self, one that can be rejected or ignored” (21). Mitchell actively asked questions and explained her motivation in joining the trial, and it is only after she is given the space to express herself that they start directing their instructions back to her (Mitchell 97). Mitchell combats this social death by joining the Alzheimer’s Society, participating in community groups, and writing her blog, further developing her social network rather than depleting it. She also advocates for people to continuing to visit AD patients in the later stages of the degree, arguing that while their memories may be limited, the emotional connection remains (Mitchell 84). Mitchell takes comfort that her sense of selfhood will remain in her continued love for her daughters, even as she struggles to remember them (Mitchell 118).
Mitchell is unique from the other authors as her social network includes people she has never met in person, but has reached through her blog. This blog initially serves as a way for her to retain the new information she has gathered on AD, but she also found a community through the comments on her blog (Mitchell 87). Kannaley et al. argued that blogs may be a way for AD patients to not only work through the emotions of living with AD, but also to connect to others as AD is often associated with isolation and loneliness (Kannaley et al. 3072). Landow argues that blogs complicate the distinction between the public and private spheres and Mitchell’s blog shows this in her combination of information about AD alongside her personal struggles and successes as she lives with the disease (81). However, Mitchell found that many people felt more comfortable reading her blog to overcome their stigmas about AD. After her diagnosis, Mitchell noticed that several of her friends stopped visiting, and later discovered that they were following her blog and it was her posts that made them feel comfortable to come and see her in person (Mitchell 154). Initially, Mitchell is hurt, but unfortunately, this reaction is fairly common and AD patients are often isolated. Eakin argues that part of this isolation is linked to the concept of selfhood as “self-narration enjoys so central a place in our living that we are conditioned to accept is as the hallmark of functioning identity,” so any struggle in regards to self-identity is often linked to no identity (48). Mitchell guesses that the reluctance of her friends to keep in contact is that AD is the reminder of their own mortality, but makes a point to “welcome them back in” once they reconnect with her (Mitchell 154). Reading these social connections in neuromemoirs relays the impact AD has on Mitchell and her family, but also the ways in which Mitchell can impact and connect to others to fight against the social death and isolation, so commonly found with AD patients.
Agency In Somebody I Used To Know

After the final diagnosis confirming her AD, there are no more doctor appointments as the doctors cannot provide any other means of treatment, so Mitchell focused on making her lifestyle changes to keep herself cognitively active and retain as much agency as possible. As with Gibbs and Saunders, she read several books on AD, and became even more active as she joined the Alzheimer’s Society (AS). Through the AS, she participated in several clinical trials and regularly speaks at events; she is often the only one present with AD. Quinn et al. notes that writings from AD patient are critical for understanding AD patients’ needs and understand how to provide the best quality of life for AD patients (2). Quinn et al. cited works like Mitchell’s Somebody are critical to providing agency to AD patients by raising concerns about those with AD who are not being heard (2). They argue for utilizing these writings as a starting point of communication for all AD patients, not just those who are formally published.

While Mitchell was originally very nervous about speaking in public and frustrated because she feels her old self would not be nervous, she found that “because people’s expectations of someone with dementia are so low that they can’t help but be impressed” when she gives her talks (Mitchell 216). She makes a point to focus on the terminology of AD patients; replacing the worder “sufferer” with a person “who lives with” AD helps combat the stigmas surrounding AD and Mitchell argues that medical practitioners need to learn to listen to their patients and give them a space to respond (Mitchell 97, 217). Mitchell also claims that she is busier than ever now after her diagnosis and even those many of these trips are stressful and difficult for her, she argues that pushing herself keeps herself active and forces her to find ways
to cope with AD rather than sitting and waiting for the disease to progress. She also finds agency in these visits as she doesn’t know when she will no longer be asked to speak or when the illness will progress to the point where she can no longer present her story (Mitchell 204). Though limited in medium, *Somebody* still connects multimodal works through these descriptions of the many projects Mitchell has worked on. This presents another connection to hypertextual works as Hayles describes the leaky boarders of the visuals in *A Humument* as connecting the work to the outside world. While Mitchell does not include visuals, she makes several connections to different mediums, blurring the boundary between her inner dialogue and her impact on the outside world (29). While there are no images in this discussion of the text, the inclusion of the current laws provides another means of viewing agency, besides the daily choices, to determining how the AD patient wants to live towards the end of their lives. Mitchell has been involved in several BBC specials on AD and has also reviewed and attended the premier of *Still Alice* the film based on the book by Lisa Genova with the same title. She also participates in the Minds and Voices program working with local officials and other locals with AD to help make York easier for people with AD to navigate the city. These examples combat the stereotype that AD patients are unable to travel or learn new things, but Mitchell still acknowledges the difficulties of living with AD.

Mitchell’s struggle to understand herself and to trust her senses makes looking into the future difficult. She states, “The me now doesn’t want to go into a care home. But what about the me that I’ll become? How will she feel about a care home? I don’t yet know her, I’ve forgotten who came before, and I can’t fully trust this me either. That’s why I prefer the now” (Mitchell 246). It’s easier for her to focus on the moment at hand, though she does rely on her daughters
and friends to help connect things or remind her of the memories she has lost. She argues “friends and family are keepers of the past, they are guardians of the bits that dementia can’t steal” (Mitchell 155). Mitchell also does not feel comfortable with having her daughters take her on a “death trip” as Saunders had considered, though she supports euthanasia as a way to end her life with dignity (Mitchell 246). She ends her work describing another moment when she becomes “foggy” while typing and must rest until she feels like she has come back to herself, showing that her life is a cycle of fighting for clarity and resting when the fog descends (Mitchell 253). This ending creates a cyclical structure that fights back against a linear narrative as the text ends, but it does not feel complete, as Mitchell is still living with AD. Though she struggles daily with the memory loss and fatigue of AD, Mitchell is able to regain her agency through her connections to her family and the AD community.

Mitchell’s *Somebody I Used to Know* utilizes technology and multimodality to describe her desire to retain her independence and adjust with her changing selves. While this neuromemoir relies entirely on print, through the letters to herself and inclusion of references to her blog, her activity within the AS, and her media and scientific contributions broaden the scope of this narrative and remind the reader of the impact AD has on the individual, their families, and their communities. Mitchell’s letter writing to her past selves also show the complicated relationship between selfhood and memory as Mitchell is unable to prevent the changes that are occurring in her brain, but continues to adapt and meet new challenges, even as she mourns what she has lost. Reading neuromemoir through the lens of hypertext reveals the interconnections between these selves and the variety of media that Mitchell presents, even through the printed medium.
Conclusion

Neuromemoirs aim to do more than simply express the author’s experience, but instead also question what determines selfhood and what aspects of our past and present experiences serve to shape our concept of selfhood. Tougaw states, “while many traditional memoirs take selfhood for granted, brain memoirs investigate how mind, brain, body, and culture interact to create or perform selfhood, and that investigation has social, scientific, and philosophical implications” (76). Rather than viewing selfhood as a consistent and set state, these neuromemoirs help emphasize the constantly changing nature of selfhood, both in spite of and due to AD. The structure of these works reflect the complexity of selfhood as the past, present, and future selves of the authors are all intersecting. As many associate AD with a complete loss of selfhood, works from authors like Gibbs, Saunders, and Mitchell are critical to provide unique perspectives on the experience of AD. These works emphasize the impact of AD on their lives without minimalizing their individuality or personhood in favor of the illness. These neuromemoirs also focus on the networks that define selfhood; arguing that even though AD is only within one brain, there is a ripple effect on the families and communities of the patients that must be addressed as well.

Though initially it may appear that there is very little in common between Neurogames, Neurocomics, and Neuromemoirs, viewing these three mediums through the lens of hypertext reveals that these works are in conversation with each other and that these printed works are more complicated in their representation of AD than they appear. Through their combination of media, their utilization of multiple voices including different versions of self, and their multiple
timelines, reading these works through the lens of hypertext is not only appropriate, but allows the readers to see multiple layers of narrative and gain a greater understanding of the author’s state of mind and thought process. While hypertext is associated with fragmentation that requires effort to transverse the narrative, hypertextual works are organized by links and associations. Bolter cites Bush’s argument about the memex and argues that hypertext could be associated with human thought, making meaning through associations rather than through linear connections (42). While hypertext is not a perfect simulation of human thought, as AD destroys cellular pathways between neurons and the neurons themselves, many AD patients rely on their ability to utilize associations when they cannot make the needed linear connections, making the application of a hypertext lens to AD narratives as a means to explore the structure appropriate. These texts provide insight into these author’s thought processes and form unique voices despite their progressive illness. These works where chosen due to their complexity in structure and organization as they explore selfhood: Gibbs through science, travel and photography, Saunders’ through her past and her relationships, and Mitchell through her new research and networks. By analyzing the form of neuromemoirs through the lens of hypertext, the authors clearly invite readers into their minds and histories in a purposefully non-linear organization to gain a better sense of who they are as a person, rather than simply as a patient.

These works also serve as a means of regaining agency in ways unique from Neurogames and Neurocomics by allowing the AD patient to regain their voice and not feel helpless after their diagnosis. Bolter argues that “writing technologies…participate in our ongoing cultural redefinitions of self, knowledge, and experience” (189). Writing neuromemoirs not only allows patients a means of coping with AD, but as a way to examine and redefine their sense of
selfhood, to reach out to others, and provide personal experiences that may address stereotypical images of AD patients and bring comfort and knowledge to others. While the comparison between mediums will be discussed in more detail in the Conclusion, it is important to note that these works are especially significant due to the fact that AD patients can write their own stories that create a record of their entire lives, not just AD, and through the act of writing, they can actively help slow the progression of their illness. These works provide a means of communication to others in similar situations or those who have a curiosity about AD or someone experiencing AD.

Rather than allowing incorrect stereotypes or frightening stigmas silence conversation or prevent someone from reaching out with questions, these works complicate the concept of selfhood and living with AD by creating an open dialogue about the process of AD. These works are inherently personal as the authors share their struggles and mourn their imagined futures; however, the readers also follow their triumphs and their determination to spread awareness and make change in both their lives and in their communities. While they have all been forced to make changes due to their illness, their neuromemoirs show that they are more than just their illness through the inclusion of their memories, experiences with loved ones, and the new knowledge they have gained through their experiences and research. These neuromemoirs show their adaptations and their refusal to give up themselves after their diagnosis, proving that growth and development of self does not stop after AD has begun.
CONCLUSION

As Alzheimer’s Disease diagnoses continue to rise, the stigmas and fear surrounding this disease limit people from learning more about the condition and also often isolate those who are diagnosed. After growing up reading writers like Oliver Sacks and V. S. Ramachandran, I wanted to focus on more narrative and patient-oriented work on this disease. I had previously published work on neuronarratives (NN) and selfhood, but as AD significantly impacts a person’s cognitive function, I wanted to focus on how selfhood and identity are expressed in AD NN. I quickly noticed similar discussion points in research on AD neuronarratives regardless of medium, but realized that discussion comparing the mediums were under-represented. While print AD NN were well-researched, comparing these mediums provided new means of approaching different representations of the disease, especially in the comparisons between the memoir, comic, and digital works. Viewing these multimedia works through the lens and medium of hypertext also revealed clear influences of digital works on printed mediums. Three works were chosen to represent each medium and I utilized content analysis to systematically review the text, images, or gameplay of the works. Combining these materials and methodology, this dissertation sought to answer the following three research questions:

1. *How do the representations of Alzheimer’s Disease patients in neuronarratives complicate our understanding of the concepts of identity and memory?*

2. *How does reading neuronarratives through the lens and medium of hypertext complicate the idea of fragmentation of memory and selfhood in these narratives?*
3. How does the modality of the neuronarratives complicate or impact the representation of Alzheimer’s Disease?

Research Question 1

How do the representations of Alzheimer’s Disease patients in neuronarratives complicate our understanding of the concepts of identity and memory?

The project answered the first question by reviewing the neuronarratives (NN) through two common approaches to Alzheimer’s Disease (AD) narratives: selfhood and social networks. As Alzheimer’s Disease is associated with the loss of identity and selfhood, this project focused on the representation of these concepts in AD neuronarratives in different mediums, revealing key similarities between the works. While there were distinct differences in the affordances of the mediums, each work emphasized the importance of the person and their experiences, rather than the disease itself. As I described throughout Chapters 1, 2, and 3, expanding on Lindsay Starck’s metaphor of stereoscopic to combine a past and present self to a kaleidoscope of selves that is constantly shifting due to AD provides a means to view these selves. Applying the kaleidoscope metaphor for selfhood in AD NN would be similar to adding more materials or colors to the kaleidoscope as these selves may only have subtle differences from the main character. These selves combined together provide more depth or variety and expand on the personhood of the main character. For example, the neurogames (NG) rarely mentioned the disease in much detail at all. Instead, these games focus on the experiences of the main character.
as the gameplay involves interactions with the main character’s belongings, which leads to dialogue or cut scenes about the main character’s past. While there are references to the disease in all three NG, the majority of the gameplay remains focused on the character’s experiences rather than how their life has changed from AD. These memories often connect to outside characters as well, emphasizing the impact of the illness beyond the main character, which also implies that selfhood cannot be expressed with only a single character. While these games do not seek to provide accurate simulations of living with the illness, they utilize narrative in their gameplay to explore representations of AD.

Unlike NG, Neurocomics (NC) emphasized the changes the illness has wrought on the main character’s lives; however, these works still emphasize the personhood of these people, rather than narrowing their experiences to just symptoms of AD. These NC were written by carers, or in the case of Roca’s Wrinkles, based on a series of experiences with AD patients. While NG included other characters to expand on the main character’s representation of selfhood, these neurocomics inherently have two perspectives: the author and the patient themselves. Though the patients are represented through the author’s voice, there are several moments of standalone images or panels that provide equal space for the patient themselves.

This structure is crucial to selfhood as this equal space allows the patient to be represented as a whole person, rather than just a victim of an illness. Due to the nature of the medium of comics, the past and present version of the patient can be shown within the same page or panel which helps maintain their identity as their ill and well selves are intermixed even as their disease progresses. These NC also emphasize how family members may preserve the personhood of the AD patient, even after they are in the later stages, and help immortalize the images of the ill and
the well selves together to represent their loved one. These NC clearly express how selfhood is not limited within the person themselves, but it created through a network of relationships and may be carried through these relationships.

While NG and NC may rely on research and personal experience to represent AD, neuromemoirs (NM) are direct writings from AD patients that also preserve their sense of selfhood and identity. Rather than following a linear timeframe from their diagnosis to their experiences today, all three of the NM discussed within this dissertation delve into the author’s definition of what constitutes selfhood and how they must view their own sense of selfhood differently in light of their diagnosis. While all three works were written by AD patients in the early stages of the disease, all three authors had already noticed the impact of the illness, forcing them to make adjustments in their lifestyles to compensate. These changes in lifestyle inherently challenge the preconception that AD patients cannot learn or grow after their diagnosis as the authors provide research for their readers and describe the lifestyle changes they enacted. Not only do they provide this new information, but the authors also utilize their previous education and experiences to re-define their sense of selfhood and all three works provide complicated discussions of what selfhood means, as the authors know that they will begin to lose their memories. These NM are critical in the discussion of selfhood and identity as they provide a voice for the AD patient and express how their sense of selfhood is changed, but not lessened due to the illness.
Research Question 2

How does reading neuronarratives through the lens and medium of hypertext complicate the idea of fragmentation of memory and selfhood in these narratives?

The second question was addressed through the examination of the structure of the gameplay, layout, and organization of these NN. Viewing these works through the lens and medium of hypertext complicates the concept of fragmentation and memory in AD NN. Fragmentation is inherent in NG as the player interacts with various elements in the environment to initiate a cutscene or prompt a dialogue that provides insight into the main character’s past. However, it is this process of reconstructing the self that complicates the idea that the AD patients are themselves entirely fragmented. While there are gaps in the knowledge provided by the AD patient, some of these prompted moments are very detailed and the main character enters into the past that is often more vivid than their current experiences. This is also seen in the memories in some of the NC, especially in Wrinkles, where the memory itself is more brightly colored and distinct from the rest of the environment.

Reading NM through the lens and medium of hypertext reveal this concept of making selfhood through this separation of selves is also present in printed works. NM can also use these hypertextual elements as the text shifts to a previous experience or utilizes elements such as italics, copies of emails, or photographs to shift into another moment in the author’s life. These multimedia elements provide clear opportunities to further separate the unique selves, but also provide new voices into the narrative, again connecting the need for social interactions to help define selfhood. These moments are also often specific memories chosen by the author to
represent an aspect of themselves that they feel is important, allowing them agency in their means of representing themselves. Viewing these moments like nodes in a hypertextual work complicates the structure and provides a means of understanding the author’s thought process in conjunction with their ideas of selfhood. This approach also provides another similarity to NG and NC as these memories may not have the color or interactive elements, but this structure allows these moments to be both part of and separate from the main narrative. Viewing these gaps through the lens and medium of hypertext reveal the amount of gap filling required to create the main character’s sense of selfhood in all of these NN. Selfhood in AD NN is not inherent, but constructed through these many selves rather than one cohesive self or a dual self representing the healthy and ill AD patient.

Another important aspect of reading these works through the lens of hypertext is the complication of linear time in regards to selfhood. Shifts to the past complicate the linearity of the plot, but these shifts make these various versions of the AD patient just as significant as the current character or narrator. For NG, these shifts are primarily through the interactions with objects, or in the case of Alzheimer’s Memories, through the mini-games; however, the player can never fully forget the main character’s current state and location. The main character will return to the current environment after the memory, or in the case of Alzheimer’s Memories, the current state of the main character will interrupt the memory, reminding the reader that the character’s perception of time is unreliable. For NC, these shifts in time either occur alongside the main plot or through panels that appear outside of the plot’s narrative with no clear connections to the main narrative. Reading these works through the lens of hypertext allows these selves to co-exist at the same time and while these selves are clearly separated, it is
impossible to fully disconnect one self from the others through this lack of linear time. The AD patients in NC are both fragmented across the pages of the work, but still unified by the narrative and images.

Both of these mediums utilize images to create these gaps for the player or reader to fill, but reading NM through the lens of hypertext also reveals gaps that the reader must actively fill as well. Though initially appearing limited due to their medium of print, it quickly becomes clear that neuromemoirs are in conversation with NG and NC through their complicated structures and use of mixed media. Unlike these works in other mediums, NM can address the experiences of feeling these different versions of themselves develop. While these authors are not able to prevent their AD from continuing to develop and instead, they must keep acknowledging these different selves, all of these versions of themselves are described by them as well. This is a critical point as it shows that not only are AD patients able to understand their condition and the symptoms that the disease imposes, but they are also able to articulate these different selves and compare themselves back to their memories of their previous selves, showing their sense of selfhood is not lost after their diagnosis. Reading these NN through the lens and medium of hypertext complicates the concept of fragmentation in AD, because while it is clear that there is loss as the AD patient notes the changes wrought by the disease, but even as these selves are separated, they remain clearly linked through the narrative. Regardless of the medium, these selves remain in conversation with each other, emphasizing the active process of creating selfhood by the author’s themselves and by the player or reader.
Research Question 3

*How does the modality of the neuronarratives complicate or impact the representation of Alzheimer’s Disease?*

It is this retention of selfhood and agency that addresses the final research question. Alzheimer’s Disease is a terrible illness and the stigmas surrounding the disease often prevent conversations about what AD is like for the patient and their carer from becoming public. These works provide a means of representing the experience of the disease or caring for an AD patient. While there is no system that accurately depicts the process of human thought, there have been many arguments that hypertext provides a means of exploring this process and creating new methods of storytelling that reflect on the human thought process. These mediums provide unique approaches to the representation of AD either through research on the illness or through personal experiences.

Viewing these works through the lens and medium of hypertext allows new means of representing AD. The NG utilize their interactive elements to represent the experiences of having the illness and represent the associative nature of the human through the interactions between the player and the game’s environment. For example, interacting with an object may connect back to the main character’s past, relationship to another person, or provide a defining aspect of the main character’s sense of selfhood. However, due the main character’s disease, there remain gaps in the player’s knowledge and even exploring every aspect of the game will not provide complete answers. This purposeful frustration is a representation of the daily struggle for AD patients who struggle with recall. Similarly to NG, NC require gap-filling from the reader, but unlike NG,
these works express the AD patients’ experiences through the eyes of the carer. NC provide a medium for carers to express their experiences caring for patients with a mix of reality and fantasy. They utilize images to express complex emotions in a small space with limited words and may use exaggerated or fantastical images to better express these emotions, while still clearly linking back to the actual ongoing events.

Though NM may initially appear more traditionally structured and limited by their print medium, these works contain characteristics of hypertext through their non-linear structure, inclusion of multimedia elements, and through their inclusion of other voices and narratives. Noting the similarities between narrative-driven games that focus on AD, NC written by AD carers, and NM written by patients themselves reveals several commonalities as they emphasize the personhood of the patient through their memories and self-reflection and highlight the importance of social networks and the impact of the disease beyond the patient. While these works don't shy away from the devastating impacts of the illness, their representations of the disease provide spaces for people going through similar experiences or those simply interested in the impacts of AD on others.

These mediums have their own unique affordances and limitations in their representation of AD. While the games provide a more interactive experience, they provide limited spaces for education of the illness compared to NC and NM. The NG described in this dissertation assume audience awareness and knowledge about the disease, which makes some of their inclusion of actual AD medication or symptoms significantly less effective if the audience is unaware of their purpose. The NC and NM discussed in this dissertation provide at least brief moments of education on AD which ensures that their readers are familiar with the basic details of the
disease. However, the NG utilize interactivity and gameplay to represent the symptoms and experiences of patients and also incorporate music and images to help direct the narrative and emotional tone of the story. NC also rely heavily on images that are able to provide inner and outer emotions and thoughts of the characters within the same panel or page. It is also well-understood that comics require gap-filling from the reader, making them more interactive than plain text. Similarly to NG, this medium also makes it difficult for AD patients themselves to write or draw their experiences as NM allow, but instead rely on the impressions of their carer to express their experiences. Due to the limitations of text in NC, some gaps may also be misinterpreted or providing scientific information may have significant limitations due to the nature of medium. NM provide detailed descriptions of AD and the diagnosis process as the authors in these works are both educating the reader, but also relaying the information they themselves researched after their diagnosis. Due to their hypertextual elements and complicated structure, without indexes or digital means of connecting sections together through links, these printed works can be difficult to navigate. While their structure provides unique insight into their thought processes, readers may struggle to follow their organization and citations or links to outside sources require outside effort to access. However, AD NM provide a unique means for patients to regain a sense of agency and control after their diagnosis and share their experiences with others. These modalities of NN provides a means for patients and those impacted by AD to express their experiences or explore unique means of representing the disease that combat the stereotypes and stigmas surrounding the illness.
Implications Of The Project

Within the scope of this project, focusing on Alzheimer's Disease NN, neuroscience has been an integral part of these narratives, but the emphasis in every narrative was the personhood of the AD patient. As described in Chapter 3, Paul Eakin argues in *Living Autobiographically*, that the act of writing about our experiences is a fundamental part of our understanding of selfhood. Writing allows us to understand our previous experiences and encode how these experiences impact our understanding of selfhood (Eakin 2). This concept is echoed in Gary Johnson’s argument for neuronarratives (NN) as works that “aspire to mimesis” or to represent a person’s consciousness through narrative, rather than a stream of consciousness narrative (Johnson 170). Johnson argues that these works are contributing to a “subgenre of literature that can provide us with a glimpse of how authors are responding to scientific advances concerning the nature of human consciousness” (Johnson 170-171). However, I argue that if we expand NN to a transmedia genre, the materials become significantly less limited and new approaches to consciousness may be explored.

Expanding NN into a transmedia genre also expands the types of media that facilitate the narrative. Comparing the affordances and limitations of the medium reveal conversations between the digital and print mediums. As I have shown in Chapters 1-3, applying the lens of hypertext or noting the hypertextual elements within the narratives complicates previously understood research on AD NN. Viewing these works through hypertext de-centers AD at the core of the narrative and instead emphasizes the personhood of the patient. The variety of mediums provide new means for players or readers to access these works and each medium.
utilizes their unique affordances to express these narratives. Expanding analytical approaches to NN provides new means of exploring selfhood and consciousness by writers, artists, and developers.

Materiality as an area of research is not novel. In his work *Between Pen and Pixel*, Aaron Kashtan argues that “...materiality is at work both when the physical and technological forms of media impact the reading experience and when the physical and technological forms of a media text are shaped by the desire to produce a specific media experience” (6). This argument suggests that when comparing media, not only is the actual medium that the work uses important, but also the impact it has on the reader. Kashtan defines “medium as a historically and culturally situated assemblage of technologies and physical parameters, which is employed for the delivery of some sort of content” (25). Though he argues that the majority of printed text are fairly uniform, I argue that viewing these works through the lens and medium of hypertext complicates this uniformity for these texts, making their materiality worthy of discussion, especially given that these AD NN focus on complicated and personal topics such as selfhood and coping with the diagnosis. Exploring these functionalities between the mediums and through the lens of hypertext creates connections that would not have been visible without this approach. Though Kashtan focuses his argument on the difference between print and digital comics in his work, using his argument to approach the printed neuromemoirs and neurocomics and the digital neurogames is appropriate to compare these different mediums.

In combination with Kashtan’s approach to print and digital comics, I also pull heavily from Katherine Hayle’s approaches to comparing different types of mediums. In “Print Is Flat, Code Is Deep” Katherine Hayles calls for Media-Specific Analysis (MSA) as a means to
compare mediums. However, she argues that this approach does not seek to isolate mediums from one another, but rather provide appropriate terminology that is not limited to the more traditional print analysis (Hayles 69). As NN are well-researched, this dissertation aimed to focus on how AD is represented in different mediums. Despite the differences in the mediums, AD NN still had many elements in common. This dissertation follows a variation of MSA; instead of one specific term, I have reviewed four common approaches to reviewing NN in the form of selfhood, social networks, agency, and for works with images, environment. While these categories may appear to be set and well-researched, by approaching these works through the lens and media of hypertext and comparing them through a variation of MSA, reveals the digital and printed AD NN in conversation with one another and complicates these categories.

Rather than viewing these NN as models of AD brains or case studies, these NN provide new representations of the disease and emphasize that selfhood and consciousness are actively made rather than an inherent understanding. By comparing how these AD NN approach selfhood, social networks, agency, and utilize environment through the lens and medium of hypertext challenges set understanding of these NN by themselves and reveals the impact of hypertext on representation of cognition and AD. NG clearly have hypertextual elements which impact how players view the cognition and representation of the disease. However, rather than viewing these works in isolation from other mediums, comparing the affordances and limitations in print media reveals that even the printed NC and NM are impacted by these digital representations of AD and remain in conversation with traditionally digital hypertext elements. Therefore, even traditional objects like NM need to be reconsidered in light of this broader lens and explored in relation to more image-based narrative and interactive works. As hypertext is
associated with both fragmentation and networks, approaching these AD NN through the lens and medium of hypertext complicates current understanding of how selfhood is represented.

Viewing these NN through the lens and medium of hypertext shows the similarities between all three mediums and places them within a dialogue with each other. As I have discussed throughout this dissertation, hypertext complicates and influences our understanding of cognition. While hypertext is not a complete or accurate representation of human thought in that we have no system that can replicate the brain’s connections and there are still many unknown factors in regards to how our brain functions, by exploring hypertextual representations of cognition, we may learn more about our thought process and how to represent that process in different ways. This topic is wide ranging, but this dissertation argues that viewing AD NN that have obvious hypertextual elements such as the NG in relation to NC and NM reveals that even more traditional printed texts are influenced by these digital elements. Though under-researched, scholars have found similarities between comics and hypertext through their composition, reliance of images and text, and the active gap filling required to traverse their narratives. Even traditionally text-based printed works such as the NM are in conversation with hypertext through their narrative organization, multi-media composition, and non-linear approach. Reading these works through the lens and medium of hypertext complicate what may initially feel like fixed approaches to these works.

Scholars such as Tougaw and Nayar have noted the importance of selfhood, social connections, and agency within AD neuromemoirs and neurocomics, but reviewing these in relation to AD neurogames complicates these set categories. As this chapter has shown, each of these mediums has its own unique set of affordances and limitations which impact how the
disease is represented within the work. The goal of this work is not to rank digital or printed works or mediums. As this work compared four major categories that are commonly studied in AD narratives between these different mediums, it becomes clear that these mediums influence how the disease is represented. As all of these works address the concept of selfhood, social networks, environment, and agency in some way within their narratives, viewing how these works relate to each other despite the variation in mediums reveals the importance of this comparative research.

Viewing selfhood through these different mediums emphasizes the concept that selfhood is made, and rather than a stagnant whole self, is often built up of many selves that reflect the experiences and changes of the person over time. While the NG show the AD patients in later stages of the condition, rather than focusing on the disease themselves, they emphasize their pasts and relationships. Though their lives have been clearly impacted by the disease, rather than present them as victims, these NG focus on their personhood as something to be valued, rather than something that has been lost. Similarly, these NC show the long-term impacts of the illness on the patients and their loved ones, but also shows how the AD patient’s personhood is carried on through others, even after they have passed. For example, while the NC Tangles shows the horrific reality of the final stages of the disease, she chooses to remember her mother through her entire life, rather than how she was when she passed. Works like these emphasize the importance of social and familial networks to combat the isolation often experienced by AD patients. These works can also help combat stigmas such as many may assume that people are unable to grow or change after a diagnosis. These NM disprove that as the authors describe their research and life changes to make accommodations for their memory loss while still living their lives. Though AD
has heavily impacted all of the people within these neuronarratives, the patient in all of them is described through their understanding of self and this re-centers them within the narrative, rather than their illness. Viewing AD NN as a transmedia genre reveals these connections between works and provides new means of exploring how selfhood is represented in response to the disease.

Another key advantage to viewing these works collectively through the lens and medium of hypertext is that it emphasizes these complex networks of connections within the works. Even if the works initially appear to be focused on one person or their family, a more detailed analysis reveals the many connections to others within the works themselves and between the different mediums. In his analysis of Building Stories, Kashtan notes the hypertextuality of the work that both emphasizes fragmentation and a complicated network. As with hypertextual works, it falls to the reader to note the connections and relationships between these fragmented scenes, the text, and the images. As Kashtan notes, while the fragmentation within Building Stories may be immediately clear through the structure, the work still relies on references to other sections within the work, indicating that even within the fragmented work, these links that create a sense of unity are also critical (159). Relating this concept to the works described within this dissertation reveals a similar structure. These neuronarratives de-center AD and the patient themselves to re-focus the concept of selfhood to the social network surrounding these families, their communities, and the wider AD community. As the disease is associated with fragmentation, reading these works through the lens of hypertext reveals these moments of fragmentation and separation, but through the incorporation of other characters through interactive elements, images, or text, also show the connections to others and ground the patients
rather that present them as lost. Though all of these works show the fragmentary nature of AD, the broader social networks provide new ways of preserving the patient’s sense of selfhood and clearly combats the ever-present fear of isolation that often occurs with a diagnosis.

As both NG and NC rely heavily on images, the environments created in these neuronarratives remain a key affordance for these works as they can express multiple things to the player or reader instantly that would take much longer in printed text. While it does take more effort from the player or reader to make these connections, these different mediums provide a variety of options to express the main character’s feelings and relationships to others. Viewing these works through the lens of hypertext shows the traversal of these works require effort by the reader and shows how these different elements come together to inform the player or reader of events that the AD patient may not reveal or is unable to remember. While NM are not able to utilize the same affordances found in NG or NC, there are some similarities between how their experiences of the disease are presented as these works can include images, jumps in time to new places or events, or use italics to imitate handwriting. While NM may seem more fixed compared to NG and NC, and they are more limited in their medium construction, by viewing these works through hypertext, these similarities become clearer and emphasize the medium as a critical component of the AD narrative. This implies that even printed works can be re-evaluated using this approach and doing so may provide new points of comparison or complicate concepts that may initially appear fixed.

Reading these works together and through the lens and medium of hypertext reveals these similarities and connects the narratives across their respective mediums. These NN pull from Rita Charon’s concept of narrative medicine to reach out to audiences by incorporating medical
knowledge alongside narratives and personal experience to simulate or articulate their understanding of AD. Though direct education of audiences may become lost within the gameplay for NG, the narrative representation of AD in these NG provide a new means of representing the disease and confronting stereotypes through these simulations. NC provides an outlet for carers to express the difficulties of caring for a loved one with the disease, but also a means to preserve their personhood even in the late stages of the illness or after they have passed. For the NM, the authors reclaim their agency in their writing as a means to combat the stereotypical views of AD patients as zombies, unable to communicate or experience a sense of selfhood. Viewing these works together reveals these conversations about agency occurring between the works despite the variation of mediums. Through their expression of agency, these NN present simulations or experiences with AD that strive to articulate this neurodivergent experience and expose both the author’s and readers’ stigmas regarding the disease.

**Limitations**

There were limitations to this study as only three works were reviewed for each medium. There is an increasing number of works that discuss or represent AD and, given that there are more people diagnosed with the disease every day, it is very likely that more materials will become available over time. There are several examples of works in these mediums such as the famous work *On Pluto* by Greg O’Brien or the illustrated *Night Bus* by Zuo Ma that were outside of the scope of this project. Other mediums such as digital comics, VR or mobile games, and films were not included. These mediums have their own unique affordances and limitations,
making them valuable for future studies. Other digital mediums such as blogs or forums could also be included for future research to review how AD patients express themselves online or how they utilize technology to help in the writing process. Michell regularly updates her own blog and there are several YouTube channels created by patients with the illness as a means of expression as well. Though the selected neurogames were discussed in detail, this project excluded printed works that were entirely fictional. As these are also important representations of AD, further research on how fictional works represent this illness would be useful as well.

Another limitation is the means of approaching these works. As this project addresses several mediums, there were numerous perspectives that could not be addressed within the scope of this project. While each chapter provided a brief literary review of the relevant arguments, a more medium-specific or field-specific approach could add more depth to this project. This also includes a more scientifically oriented approach to review the neuroscience in these specific works or within the mediums as a way to measure the accuracy or commonly misunderstood concepts. As NN exist within the intersection of the humanities and the sciences, more multi-discipline research is needed to explore these representations of AD in multiple mediums.

**Areas For Future Research**

Continuing to research how digital and print NN influence our perception of selfhood, cognition, and AD is necessary to continue to explore how medium impacts our representation of the brain. As the AD population continues to grow, expanding NN as a transmedia framework through the lens and medium of hypertexts widens a means of self-expression and exploration
the representation of consciousness. As the disease is associated with a loss of selfhood, these works push back this stigma and re-center the person, rather than the disease, as the focus of the work and provides a voice for AD patients and caregivers. Expanding the types of mediums from those described here would provide further points of comparison, but also explore new means of representing the experience of the illness, especially those that continue to mix digital elements.

There are also aspects of NN that were outside the scope of this dissertation, such as NN’s potentially problematic representation of mental health and their relationship to disabilities studies. While discussing printed narratives, Tougaw argues that “narrating from a neurodivergent point of view is a kind of formal niche construction, creating a story built on the cognitive perspective of the narrator” (135). While the term neurodiversity is more commonly associated with autism, the term can refer to any person with mental or neurological functions that vary from the general population. Authors such as Shibley Rahman with the Dementia Society have been advocating for dementia to be considered a form of neurodivergence as a way to break down some of the stigmas associated with dementia and AD. However, this may not be enough as Yerheau notes in *Authoring Autism*, works about conditions or perceived disabilities can hyper-fixate on aspects of those conditions without taking into account the impact of the people being discussed. This is particularly problematic as Yerheau argues, “it is impossible to deny that the arguments structing public knowledges, understandings, and felt sense of autism are grossly ableist, powerfully violence, and unremarkably nonautistic” (5). This claim raises concerns regarding AD NN as well as it is possible that these works can continue to spread stereotypes or incorrect information that are ultimately more harmful to AD patients. Ortega and Vidal note that NN should not be considered “disability counternarratives” and that NN may
disassemble their characters to simple “cerebral subjects” rather than as a representation of a person (350-351). Several authors such as Tougaw and Roxburgh et al. raise concerns about “neuromania” or the oversimplification of neuroscientific concepts as a means for an interesting narrative, rather than a study of the people impacted by the condition. These are all valid concerns that are inherent in any research of a neurological condition, especially in a field where there is a mix of fiction, personal accounts, and autobiography in works that appear in a variety of media.

Some authors have already addressed these issues on similar topics. In her work *American Lobotomy*, Jenell Johnson addresses the mix of inaccurate information and medical fact in the history of lobotomy. Rather than separate the reality from the fiction, she notes how meanings of the medical procedure have changed over time from a valid medical treatment to a horrifying punishment (Johnson 4). Johnson notes that in her research of American perception of lobotomy, “the perceived horror of the procedure and the medical reality are intertwined” (7-8). I argue that a similar case can be made for Alzheimer’s Disease as it is a horrific disease that slowly takes away a person’s memories and bodily functions until they die. This disease results in a complete loss of independence and agency that is particularly feared in Western culture as the desire for autonomy is coveted. However, this fear of the horrors of the end stage of AD has resulted in silence and stigmas around the disease, rather than providing a means of open communication. NN provide a means for this communication. As Johnson researched the representation of lobotomy in medical writings, personal accounts, and in physical locations like asylum tours, this dissertation aimed to research the different mediums of AD NN. As discussed in the Limitations section, there are many other mediums that would provide valuable insight.
into the representation of AD in NN that could expand on the research discussed here. Though not without flaws, NN provide a means for those impacted by the illness or curious about the disease a means to explore and understand the condition. Researching the way these different mediums represent Alzheimer’s Disease provides new ways to express selfhood and complicates our representations of the illness.
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