2022

Science and Sadness: Critiques On How We Handle Alzheimer's Disease and Dementia

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Science and Sadness: Critiques On How We Handle Alzheimer's Disease and Dementia

An Honors Thesis

Presented to

The Faculty of the Department of Science, Technology, and Society

Colby College

In partial fulfillment of the requirements for the

Degree of Bachelor of Arts

By

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Waterville, Maine

May 9, 2022

Abstract

In our society, an individual's worth is tied to the state of their cognitive function which affects the discourse about neurodegenerative illnesses, causing it to mostly fall under two branches: "The Dread" and "Science as the Holy Grail". "The Dread" addresses how Alzheimer's Disease (AD) and other dementias are typically perceived as devastating illnesses to be feared. "Science as the Holy Grail" represents the hope and faith that is invested into potential technoscientific developments without the guarantee of any consequential results. Limiting the narrative to these two categories negatively impacts the quality of life (QOL) of AD patients, caregivers, and families. Disciplines such as music, art, and literature, are not traditionally consulted as ways of helping AD patients and caregivers. The majority of resources available for AD and dementia are designated to support scientific studies and research projects that anticipate the development of solutions in the *future*. Putting monetary and labor resources into science has been disappointing so far. It is unlikely that the humanities will find the cure for dementia but investing time and energy into alternative approaches could yield some *real time* solutions directed towards improving QOL for AD and dementia patients and caregivers. Through analysis of a graphic novel and an artist's self portraits, I honed in on some of the ways that people affected by AD and dementia could really benefit from what the humanities has to offer and to showcase what different humanities-based therapies have already been able to achieve for dementia patients.

Keywords

Alzheimer's Disease, dementia, quality of life, humanities, dementia care

Acknowledgements

Throughout the writing of this thesis, I have had the support of a village. First off, I would like to thank my science, technology, and society (STS) senior seminar instructor, Professor Ashton Wesner. Since we first met to discuss project ideas, Ashton has been nothing but encouraging and helpful. From lessons on STS methodology to bird species identification PowerPoints, being in her class has only ever heightened my appreciation for the field of STS and confidence in my choice to complete this major.

I would like to convey my sincerest gratitude to my second reader, Professor Jay Sibara. During my years at Colby, Jay has been a wonderful educator, mentor, and friend to me. He introduced me to the field of medical humanities and has helped me explore a passion I never knew I had. I am forever thankful for his feedback and consolation on this project.

I would like to acknowledge my classmates. Despite each of us having what feels like completely different thesis topics, it has been such a pleasure to go on this year-long journey with all of them. There is a special kind of bond that forms amongst people that embark on what sometimes may feel like an impossible and never-ending task. I am really grateful to have had the opportunity to grow and learn with such a special group of ambitious people.

Thank you to the friends who have inspired me or were kind enough to share that they also had a loved one suffering from some kind of dementia. Because of them, I have felt less alone and more compelled to conduct this research. A special thank you to Harry Kassen for introducing me to an artist whose portraits would end up becoming one of my primary materials.

I would like to thank my mother and grandmother. They have molded me into the person that I am today and have provided me with the love, guidance, clarity, and motivation necessary to take on a project like this. Te quiero mucho, Mami. Te extraño, Abuela. ♥

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Preface

My grandmother was my everything. She played a huge role in raising me. My mom was a single mom and she was the breadwinner of the household. That meant that it was just me and my grandma most of the time, until age five when I started going to school. When I was fifteen, my grandmother started to experience symptoms of Lewy Body dementia (LBD). The onset of her condition was especially hard to accept. No one in my household understood what was happening. My mom and I thought my grandmother was messing with us. We thought she was doing weird things on purpose. Sometimes we would laugh but other times we would get angry. It was complicated and painful for the three of us.

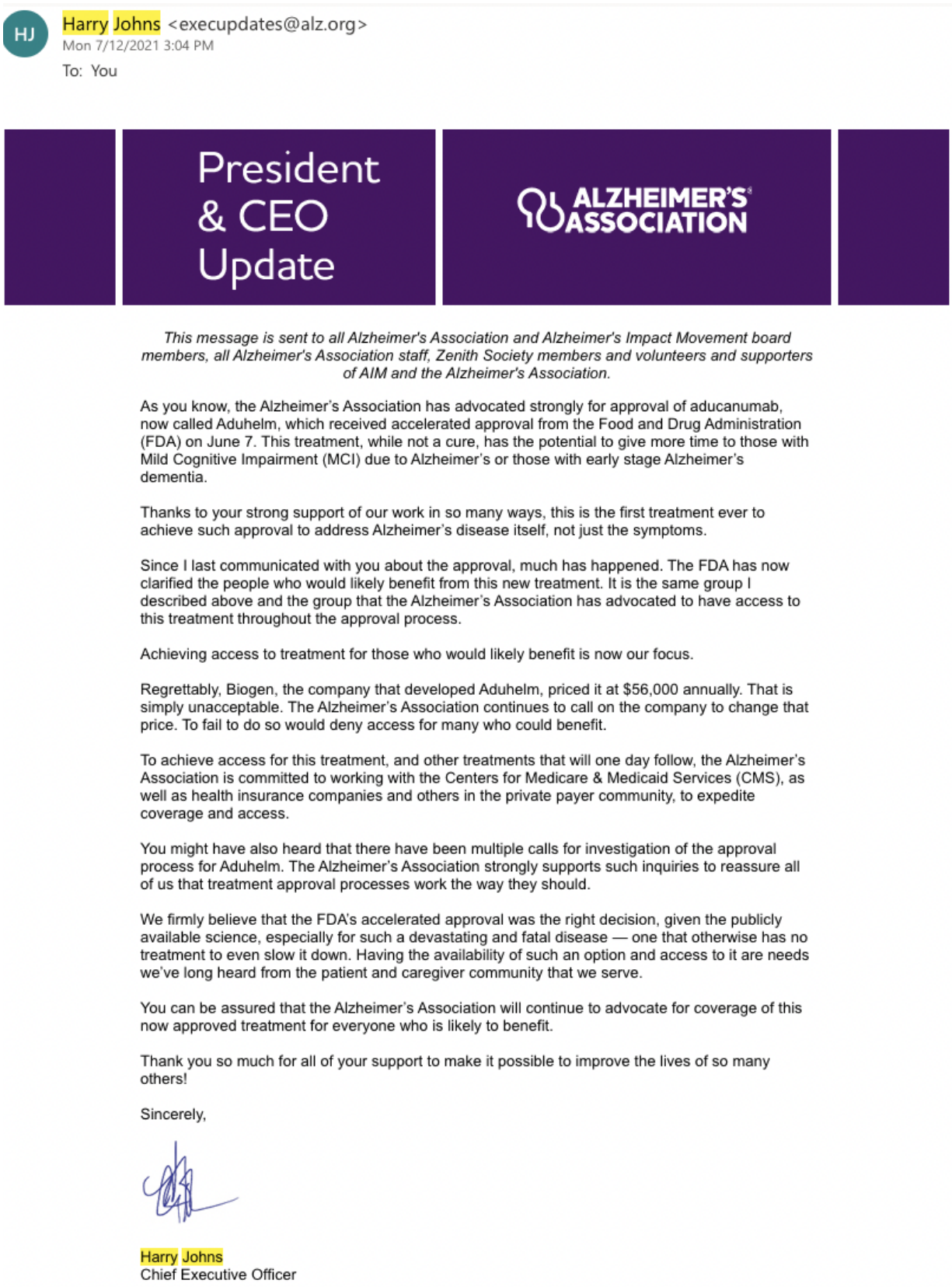
Eventually, my grandma was diagnosed and new challenges arose. New challenges arise to this day. It's been seven years. My mom and I still grieve. Grieving someone who is still alive is a pain unlike no other. It is heavy and consistent. There is no moving on. There is no comfort in the idea that she might be in a better place now because she is still here with us. You have to deal with your pain every day; it just so happens that your pain stems from someone you love, that you don't know anymore, that has become someone else. You drive yourself crazy doing the things she can't do anymore: thinking and remembering. Thinking of potential whys, reasons, and solutions. Remembering her wisdom, her warmth, her laughter. You think to yourself "she is still alive so there *must* be something we can do." But there isn't. That doesn't stop you from, metaphorically, banging your head against the wall to see if one day, if you just think hard enough you might come up with something to fix it.

Acceptance is difficult. It never really comes but if it does, it only visits. Acceptance is temporary and often happens when you are tired. Tired of thinking and remembering. Tired of feeling sad or angry. So, you decide to give acceptance a try and attempt to cope. But, just when

you think you've figured out the whole acceptance and coping thing, you might remember a moment or see an old photograph. A wave of sadness will take over and you are left not knowing what to do with yourself. For me, not knowing what to do with myself usually manifests into an idea or action.

The first time I had an "idea", I was sixteen. I decided that I wanted to raise money for the Alzheimer's Association (AA). I really believed in their mission and I wanted to start my own fundraiser. And I did. I made my own fundraising page. I posted about it on my social media accounts and I talked about it every chance I got. By the end of it, I was able to raise $100. To me, this was huge. $100 was a lot of money to me. It still is. I felt empowered because I did it all on my own. People in my immediate family didn't believe in what I was doing. They told me I wasn't going to meet my fundraising goal and they ended up being wrong. This was my way of making a small difference and I did it for my grandmother. I did it because I believe in science. I believe in the power of research and I hope that one day the AA's goal of ending dementia comes to fruition.

I have been on the AA's emailing list for many years. All of their emails are structured similarly. They'll include a cute or devastating story about a family who has a loved one with Alzheimer's, they'll tell you about the latest scientific research findings, and they'll end the email by asking you to donate money. After so many years of receiving these emails, they can get kind of annoying. Sometimes, reading them feels like a slap in the face. Before continuing, please know that my intent is not to bash the AA. I actually think they do great work. My intent is only to tell the origin story of this thesis paper, also known as my second "idea".



HJ

Harry Johns <execupdates@alz.org>
Mon 7/12/2021 3:04 PM
To: You

President & CEO Update

ALZHEIMER'S ASSOCIATION

This message is sent to all Alzheimer's Association and Alzheimer's Impact Movement board members, all Alzheimer's Association staff, Zenith Society members and volunteers and supporters of AIM and the Alzheimer's Association.

As you know, the Alzheimer's Association has advocated strongly for approval of aducanumab, now called Aduhelm, which received accelerated approval from the Food and Drug Administration (FDA) on June 7. This treatment, while not a cure, has the potential to give more time to those with Mild Cognitive Impairment (MCI) due to Alzheimer's or those with early stage Alzheimer's dementia.

Thanks to your strong support of our work in so many ways, this is the first treatment ever to achieve such approval to address Alzheimer's disease itself, not just the symptoms.

Since I last communicated with you about the approval, much has happened. The FDA has now clarified the people who would likely benefit from this new treatment. It is the same group I described above and the group that the Alzheimer's Association has advocated to have access to this treatment throughout the approval process.

Achieving access to treatment for those who would likely benefit is now our focus.

Regrettably, Biogen, the company that developed Aduhelm, priced it at $56,000 annually. That is simply unacceptable. The Alzheimer's Association continues to call on the company to change that price. To fail to do so would deny access for many who could benefit.

To achieve access for this treatment, and other treatments that will one day follow, the Alzheimer's Association is committed to working with the Centers for Medicare & Medicaid Services (CMS), as well as health insurance companies and others in the private payer community, to expedite coverage and access.

You might have also heard that there have been multiple calls for investigation of the approval process for Aduhelm. The Alzheimer's Association strongly supports such inquiries to reassure all of us that treatment approval processes work the way they should.

We firmly believe that the FDA's accelerated approval was the right decision, given the publicly available science, especially for such a devastating and fatal disease — one that otherwise has no treatment to even slow it down. Having the availability of such an option and access to it are needs we've long heard from the patient and caregiver community that we serve.

You can be assured that the Alzheimer's Association will continue to advocate for coverage of this now approved treatment for everyone who is likely to benefit.

Thank you so much for all of your support to make it possible to improve the lives of so many others!

Sincerely,

Harry Johns
Chief Executive Officer

Fig 1. Harry Johns; "President and CEO Update"; Alzheimer's Association, 12 July, 2021; email.

The one email that really was the catalyst for initial conversations about this project was from Harry Johns, the CEO of the AA, on July 12th, 2021 (see fig. 1). This email served to announce the FDA's approval of aducanumab, or Aduhelm. Aduhelm is the first ever FDA approved treatment that actually addresses Alzheimer's Disease (AD) itself (see fig. 1). Other AD medications prior have only been able to address the symptoms of the disease. Johns continues his letter by telling us how Biogen, the company responsible for developing Aduhelm, is charging AD patients $56,000 annually for their drug (see fig. 1). The fact that pharmaceutical companies can charge an absurd amount of money for medications that many people could really benefit from is atrocious. That could be the topic of a whole other thesis paper and is certainly not within the jurisdiction of the AA. At the same time, it is known that the AA works to increase the amount of funding that the government allocates towards AD research every year. With the $3.2 billion that the National Institutes of Health (NIH) is expected to spend on AD research in 2021 alone, one would think that there would be more treatment options for AD patients (Alzheimer's Association). Instead, we have a single medication that most AD patients would not be able to access anyway. Given this context, one might understand why it is disappointing or frustrating to receive emails that brag about *new* and *exciting* scientific findings that give us hope for the future, immediately followed by the request for donations, time and time again.

The reason why these emails feel disrespectful is because they don't address the everyday problems. Science is often focused on finding solutions to "big" problems. The "big" problem in this case is the need to cure neurodegenerative diseases like AD. Science is not concerned with the "little" problems that patients and caregivers face on a daily basis. The reality is that these "little" problems feel really big to us. They feel insurmountable and lonely. An example of a

“little” problem could be the grief I was describing earlier. Science cannot alleviate that but there are other things that can.

During my first semester of college, I was looking for another way to put my pain to good use. I wasn’t interested in fundraising for the AA anymore. On my quest for an outlet, I came across a volunteer group called Colby Legacy Storytellers. Every week, my volunteer partner and I would visit a local assisted living facility and we would speak to an assigned patient, who I’ll call Mary. Mary was in the preliminary stages of AD. Our job was to ask Mary questions that would prompt her to tell us about her life and we would record these conversations. Towards the end of the semester, we transcribed these sessions, wrote a story, and found pictures to include in a little book about Mary’s life. At an end-of-the-year celebration, my partner and I got to meet Mary’s family (with Mary in attendance) and present them with the book we made to document Mary’s life. We read the book out loud together. I watched Mary’s relatives smile, laugh, and some even got emotional. There was power in the narrative my partner and I wrote. It is a tangible record of the wonderful person that Mary was and the awesome life she lived. It is something Mary’s family will always have and be able to refer back to as Mary’s illness progresses.

Volunteering with Colby Legacy Storytellers was one of the best experiences of my life. What I was able to do for Mary’s family was something I desperately would have wanted someone to do for my family during the early stages of my grandmother’s prognosis. It would have provided great comfort to my mom and I when we needed it most. I tell this anecdote only to describe an act that was not very scientific at all but yielded great results, nonetheless. Storytelling and photography are examples of cultural productions that are highly likely to provide relief when one is experiencing tremendous loss or hardship. Yet, it is uncommon to turn

to such cultural productions as a line of defense. Instead, we heavily rely on science to somehow produce the relief we so desire, through invention, discovery, or the acquisition of knowledge, which are all much less likely to occur. I write to illuminate how backwards this is and how shifting our focus, at least partially, to the humanities could significantly improve the quality of life (QOL) of so many patients, caregivers, and families.

Introduction

Music, art, and literature, are resources that are not often highlighted as ways of helping AD patients and caregivers. In this paper, I argue that it would be a good use of the time and energy available to AD patients, and the personal and medical communities surrounding them, to increase accessibility to humanities-based resources. Through analysis of a graphic novel and an artist's self portraits, I hope to hone in on some of the ways that AD and dementia patients and caregivers could really benefit from what humanities genres have to offer. Most, if not all, of the money for AD and dementia goes to funding different scientific studies and research projects that will develop solutions for us in the *future*. Instead of putting everything we have (i.e. funding and faith) into science, it might be wise to allocate some of those resources into the humanities. One of my primary goals in the writing of this thesis is to showcase what different humanities-based therapies have been able to achieve for dementia patients and to emphasize how leaving such therapies out of care plans is doing these patients an enormous disservice.While the arts, for instance, will likely be unable to find a concrete cure for dementia, they could yield some *real time* solutions by improving the QOL of AD and dementia patients and caregivers, which is just as valuable as the latest drug developments, perhaps even moreso.

The discourse surrounding AD and dementia in our society can be broadly classified as pertaining to either one of two categories: "The Dread" and "Science as the Holy Grail". When talking about AD and dementia, the first thing that comes to mind for many people is how prevalent these illnesses are becoming. Prevalence does not necessarily need to be defined by statistics. In everyday conversation, AD and dementia prevalence is increasingly noticeable. It is not uncommon to bring up AD and for someone to say something like "my friend's grandpa had that" or "my grandma currently suffers from AD." After someone suffering from the disease is

identified, the conversation might continue until someone says something along the lines of, "yes, it's been awful watching them deteriorate" or "taking care of them has been extremely difficult." Not to say that it should be, but the conversation is never really pleasant. It is, more than anything, *sad* and surrounds the devastation of having a loved one or knowing someone who is affected by dementia.

Countless videos on YouTube exploit the sadness of AD. The title of the video is almost always "Jane Doe's Story: Living with Alzheimer's Disease." These videos usually show clips of the patient with AD exhibiting some of the classic symptoms, confessional style footage of the family members detailing how long it has been and how sad it makes them to have to watch their loved one completely change, and confessional style footage of medical professionals giving scientific facts about the disease. The goal of these formulaic videos is to gain sympathy from the audience. The formula works. These videos are tear-jerkers, for sure. However, the devastating narrative that is portrayed does not acknowledge the happiness in between the sadness. The journey that patients affected by AD and their caregivers go through is not sorrowful the entire time. As unlikely as it may seem, there *are* moments of appreciation, laughter, and gratitude, woven in throughout the duration of the illness.

In this society, we tie self worth with cognitive function. If cognitive function is lost, the individual loses their ability to produce. Therefore, their worth and the value that they should inherently have is diminished. It only makes sense that people would *fear* getting AD in response to this phenomena. In the preface of his book *Self, Senility, and Alzheimer's Disease in Modern America*, Jesse F. Ballenger details his experience working as a nursing assistant in the 80s and explains how "the destruction of brain tissue [associated with AD] entail[s] a destruction of abilities and qualities essential to people's identity, if not to their very humanity", which he

witnessed in some of his own patients (Ballenger ix). Ballenger also provides insight into how people with AD are often described by others: "as 'hollow shells,' as 'no longer really there,' as having somehow already died despite the troubling persistence of an animate body" (Ballenger x). Such a description can be really disheartening, especially for caregivers. If the patient is 'no longer really there', then who are they working to keep alive? Who are their blood, sweat, and tears, serving? A memory of someone who used to be? Keeping the mere memory of a person alive should not demand this much effort.

From the get-go, Ballenger claims that the *dread* surrounding dementia, "has helped to shape knowledge about dementia, health policy, and the experience of caregivers and people with or at risk for dementia" (Ballenger 1). The dreadful story that has been created for AD over time has real-life implications. Limiting the characterization of an illness to *only* being able to be thought of as depressing and grief-inducing affects the kinds of options and opportunities that are available to patients and their families. Moreover, changing the discourse to one that is more accurate and well-rounded would aid in efforts to humanize AD patients and allow them to live with dignity. To be clear, the goal is not normalization. Dementia should never "be considered a potentially natural part of growing old" (Zimmermann 394). All the money and effort going towards one day finding a cure would be in vain if that was the case. People dedicate their whole lives to finding a cure, whether that be through science or activism. Losing oneself should not be what people prepare for as they age. Instead, the new narrative should be all encompassing. It should include fear, dread, sadness, *and* the moments of joy, humor, and peace.

Given the depressing nature of the dialogue surrounding AD and dementia, people need something to hope for, something to look forward to. Science fills that void. On the AA's website, one of the listed ways for good Samaritans to "get involved" is to advocate for research

funding. There, they literally state: “Alzheimer’s is a devastating disease impacting millions of families and our nation’s economy. The *only* way to change this is through research.” (Alzheimer’s Association). The language used by the AA positions science to be viewed as the end all be all for AD. By positioning science as the *only* means for change, it becomes easy for other change-making methods to be disregarded or ignored. In isolating research outcomes as the only entity that AD patients and families have to be hopeful about, science becomes, what I call, the holy grail.

As briefly mentioned in the preface, the NIH *alone* spends billions of dollars every year on AD research. Considering how heavily funded AD is, one would think that there would be more treatment options for AD patients. Research is expensive, time-consuming, and does not always supply significant results. In the 2018 article “Asking the Right Questions in Alzheimer’s Research”, Susan Fitzpatrick accurately summarizes the true effects of putting science on a pedestal as the primary path towards a solution to the AD-dementia problem:

> Forty years into a full-on effort to defeat Alzheimer’s disease as a major cause of cognitive decline and death—indeed, it is the sixth leading cause of death in the United States, afflicting nearly six million people and wreaking enormous emotional and financial tolls on patients and families—this is where things stand: we have no treatments, and though efforts to improve early-stage diagnosis have had some success, their main impact is to inject enormous new uncertainties and anxieties into a patient’s view of the future and sense of self (Fitzpatrick 77).

Of all the resources we have to aid the patients and families dealing with dementia, the majority of them go towards science. The idea is that science will solve all our problems. We are supposed to believe in how the next study, the next drug, the next therapy, will drastically change the lives

of AD patients and their families. The reality is that there is no guarantee that there will be a new drug or therapy. Even if there is one, there is no guarantee that it would actually be accessible to that many AD patients. Putting all faith into science is misleading and leads to disappointment for all the AD patients and families that are really depending on potential scientific innovation.

Regardless of the unimpressive outcomes that technoscientific developments might offer, that seems to be the first place that people turn to for answers and solutions. The environmental sociologist, Laurent Cilia, writes about a similar problem as it pertains to bees and beekeepers. In his 2019 article, *'We don't know much about Bees!' Techno-Optimism, Techno-Scepticism, and Denial in the American large-scale Beekeeping Industry*, Cilia plainly defines "techno-optimism" as "the faith in technology and science" which was originally derived from Enlightenment philosophers' "call for reason" (Cilia 85). Cilia explains how beekeepers have leaned into techno-optimism, and techno-imaginaries in general, since the survival of the bees directly affects their own livelihoods (Cilia 85). Referencing a study done by Kulhanek et al., Cilia acknowledges that "science has made little if any measurable progress on the global health of honey bees since the beginning of the [Colony Collapse Disorder] crisis in 2006 [but] losses remain concerningly high, [begging] the question of whether this is the right approach to the issue" (Cilia 85).

AD patients, families, and caregivers, are implored to fall into the same unsubstantiated techno-optimism. Much like with honey bee health, science has made little progress on understanding why and how dementia occurs, let alone how to treat it. Medications doctors prescribe to dementia patients are generally antidepressants and/or antipsychotics. Dementia-specific drugs still do not exist. Because of the insanely complicated and long process that it is to develop medications, there is no use in waiting around for that to happen. While we

wait, people are still suffering and the daily struggles of living with AD or living with a loved one that has AD remain unaddressed. Moreover, relying on the development of new medications as the only potential remedy to the dementia problem disregards a more holistic approach at treating dementia.

The truth is that AD and dementia *is* sad. There is currently no way to prevent the unraveling of the mind caused by such neurodegenerative diseases. However, we must consider the direct material implications that this dreadful narrative cultivates. If there is no solution to a problem and it is going to be devastating no matter what, then what is the point in devoting resources to that problem? Limiting the way that AD is thought and talked about, in turn, limits the options available to patients and families. As a society, we must get creative and think outside of the scientific box that we sometimes put ourselves in. Only then does the experience of patients and caretakers alike have the possibility to improve.

Before all else, it is imperative that an individual's worth is untied from their cognitive function. Thinking about personhood in the context of mental status is unjust and outdated. Every life has inherent value regardless of a person's mental or production capabilities. I will be exploring this idea through the analysis of William Utermohlen's art, specifically a selection of some of his self-portraits. Additionally, there is strength in AD patients, caregivers, and families telling their own stories. Personal stories can do so much for the healing of those that know the loss of neurodegenerative illnesses; it is crucial that they know they are not alone and that their experiences are not isolated ones. In an examination of Sarah Leavitt's graphic novel, *Tangles: A Story About Alzheimers, My Mother, and Me*, I am seeking to convey the merit that storytelling has in bettering the QOL for all those affected by AD and dementia.

Background

Dementia is an umbrella term used to describe a group of neurodegenerative illnesses that impair the ability to think, remember, and make decisions (Alzheimer's Association). AD is the most well-known kind of dementia because it accounts for 60-80% of all dementia cases (Alzheimer's Association). AD is arguably the most talked about and heavily funded form of dementia, as well. The Alzheimer's Association has contributed to this by doing an especially good job at raising awareness about AD over the years. What isn't well known about AD are the origins of the disease.

Progressive cognitive impairment, a hallmark characteristic of AD, is a pattern that has been identified and associated with elderly patients, stretching back centuries (Ballenger et al. 47). Dementia as a whole was characterized by clinicians about fifty years prior to "Alzheimer's time" (Ballenger et al. 47). Yet, AD, specifically, could not have been fleshed out as a scientific concept until the early 1900s because certain processes needed to be invented to make AD definition possible, such as the development of "techniques to preserve the brain for examination and to process tissue in a way that microscopic evaluation could be conducted" (Ballenger et al. 48). Thus, AD couldn't have been detected or defined prior to Alois Alzheimer's lifetime. The man that the disease is named after needed to grow up and finish his studies before his curiosity and ingenuity would lead him to the patient case report that would result in his surname being commonly referred to, for so many decades after him.

Following his graduation from medical school in 1888, Alois Alzheimer went to the Municipality Asylum for the Mentally Sick and Epileptics in Frankfurt, Germany where he was mentored by the "liberal psychiatrist" Dr. Emil Sioli (Ballenger et al. 6). Alzheimer ended up becoming very interested in psychiatry himself and found himself eager to incorporate his love

of microscopy into the field (Ballenger et al. 6). The opportunity arose when “the number of mentally ill patients [began to increase rapidly] in Germany” and Dr. Franz Nissl came to Frankfurt after discovering “better tissue-staining techniques” (Ballenger et al. 6). The friendship that Alzheimer and Nissl formed in the 1890s after doing research together in Frankfurt helped get Alzheimer connected to the psychiatry researcher Emil Kraepelin in Heidelberg (Ballenger et al. 6-7).

Ultimately, Alzheimer went to Heidelberg to work on a research project with Kraepelin after deciding that he wanted to try and combine his clinical work with research (Ballenger et al. 7). After developing this relationship with Kraepelin, Alzheimer followed him to Munich where he would end up being the “head of the neuroanatomic laboratory” at “the Nervenklinik” (Ballenger et al. 7). Nervenklinik ended up becoming a central place for many “renowned psychiatrists and neuropathologists” to meet up and work on research together, including the making of “thousands of microscopic preparations” (Ballenger et al. 8). His position at Nervenklinik set the scene for Alzheimer to work with Gaetano Perusini, who would help him write the descriptions about the first documented AD patient: Auguste Deter (Ballenger et al. 8, 10).

Auguste was “a 51-year-old woman from Frankfurt[, Germany]” who’s symptoms included “progressive cognitive impairment, focal symptoms, hallucinations, delusions, and psychosocial incompetence” (Ballenger et al. 5). After her death in 1906, “Alzheimer asked that [her extensive patient] record and [her brain] be sent to Munich” where he would analyze the brain in his lab and determine that August was also presenting “arteriosclerotic changes, senile plaques, and neurofibrillary tangles” (Ballenger et al. 5, 19). In 1907, he held a lecture about his case-study on Auguste, at the annual Southwest German Psychiatrists meeting in Tübingen,

which was eventually published in a journal "under the title, 'A Characteristic Serious Disease of the Cerebral Cortex'" (Ballenger et al. 20). A few other reports came out after that discussing the same disease and referencing his paper (Ballenger et al. 21). The culmination of these publications later influenced Kraepelin to mention AD for the first time ever in "the eighth edition of his *Handbook of Psychiatry* (1910)" (Ballenger et al. 21).

Despite the inclusion of AD in early 20th century publications, "none of the involved psychiatrists… provided clear-cut definitions of" AD (Keuck 12-13). AD was only vaguely described and the "'peculiar [patient] cases'" meant to serve as evidence of AD's discovery could have also been considered "atypical forms of senial dementia" since AD was so loosely defined at the time (Keuck 13). This left room for discussion about the validity of early AD findings and much needed to happen before AD could become the so-called "social disaster" we now know today (Ballenger et al. 49).

Through the early 1930s, the goal of clinicians then became to distinguish AD from "normality" (Ballenger et al. 48). Apparently, the "histopathologic study of brain tissue [was not enough] to establish solid ground for this distinction" (Ballenger et al. 48). In the 1940s and 1950s, psychosocial approaches to dementia were of primary interest but those methods were withdrawn in the 1970s when "biological models" became resurgent and tools like electron microscopy and neurochemistry were more widely available (Ballenger et al. 49). The shift towards biology-centered means of understanding AD might also explain why AD "was rarely diagnosed until the mid 1970s" (Keuck 11). The 1980s marked when AD "began to be ranked among the ten most common causes of death in the United States" (Keuck 20). In the 21st century, genetics has taken over and that is the lens by which AD is looked at now (Ballenger et al. 50). The development of Sanger sequencing, and its commercialization in 1986, allows for the

identification of specific sequences in DNA (Wikipedia). With the use of Sanger sequencing in and through the operation of the Human Genome Project (1990 to 2003), researchers are able to compare specific DNA sequences in order to assess an individual's genomic mutations against a norm. Continuing into the present, the predominance of genetic understandings of disease have meant that approaches to AD are focused on analyzing genetic inheritance and developing genetic therapies and interventions. Aside from the metamorphosis of AD conceptions over time, socially and scientifically, the suffering that AD has inflicted on so many generations of people remains constant.

In the preface of this paper, I briefly mentioned that my grandmother suffers from LBD. The choice to center my research on AD and dementia in general, as opposed to having a focus on LBD, stems from LBD not being as well known. LBD only accounts for 5-10% of all dementia cases (Alzheimer's Association). Even though approximately 1.5 million people are suffering from LBD in the US, it is still significantly less common than AD (Williams 1308). Recently, LBD has gained some kind of notoriety after the passing of the beloved actor, Robin Williams, in 2014, who was devastatingly affected by this illness. As a matter of fact, I recently suggested to my systems neuroscience biology seminar professor that I wanted to do my semester presentation on LBD and he replied "Oh! Isn't that the dementia that Robin Williams had?" Still, the loss of the esteemed comedian and actor a number of years ago is not enough to increase the public's awareness of LBD to the same extent that AD is commonly familiar. Research articles and books on AD are much easier to find. Because my argument is applicable to all kinds of dementia, it is not necessary for all of my evidence to be specifically about LBD. Nevertheless, it is important to point out that LBD and other dementias have their own unique histories and hallmark features that differentiate them from AD.

According to the IHME, neurological diseases, as a whole, accounted for approximately 2.21% of total DALYs in the year 1990 (see fig. 2). DALYs (Disability-Adjusted Life Years) are a "measure of [the] burden of disease in a population" (Carlson, slide 6). DALYs are the "number of years of healthy life lost in a population due to premature death and disability" (Carlson, slide 6). By 2019, total DALYs, as a result of neurological diseases, have almost *tripled* and account for about 6.16% of total DALYs overall (see fig. 2). AD and other dementias alone accounted for 0.45% of total DALYs in 1990 (see fig. 2). By 2019, AD and other dementias accounted for 2.19% of total DALYs (see fig. 2). In nearly 30 years, the percent of global DALYs attributable to AD and other dementias has *quintupled* (see fig. 2).

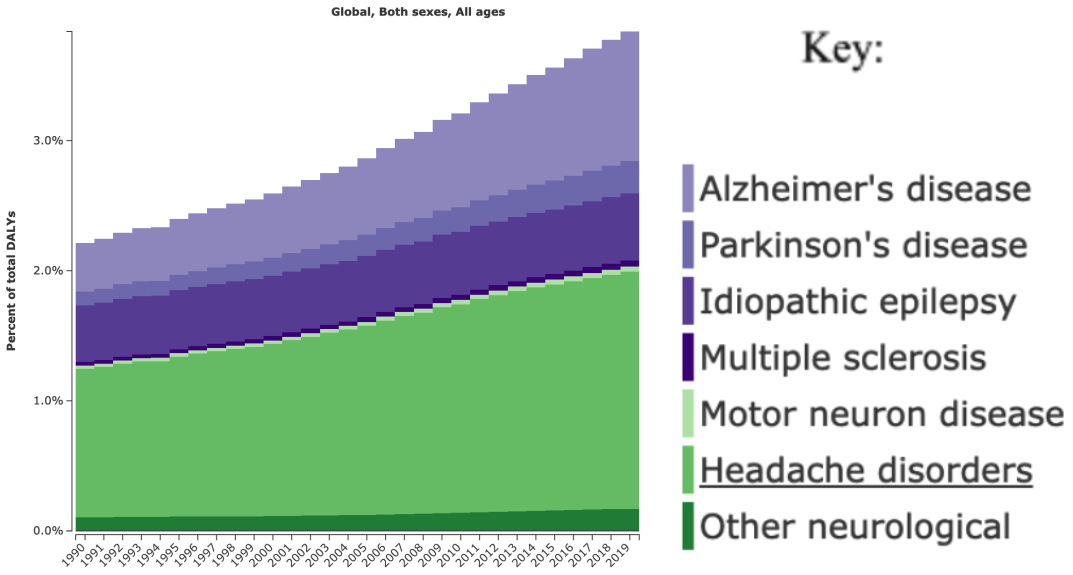


Fig 2. IHME; "Global Burden of Disease (GBD) Study Results." *Institute for Health Metrics and Evaluation*, 2019, https://vizhub.healthdata.org/gbd-results; graph.

AD and other dementias are immense global public health threats. When looking at a world map depicting DALYs from AD and other dementias in 2019, it is clear that the majority of DALYs are concentrated in more developed countries, such as Japan, Canada, and Spain (IHME). Even so, no one is guaranteed to have immunity from AD, even if the risk is extremely

low for youths. For people with late-onset AD, symptoms usually start to appear in patients during their mid-60s (NIA). Patients suffering from early-onset AD might start to experience symptoms anytime betweens their 30s to mid-60s (NIA). There are several stages of AD and symptoms vary according to the stage that the patient is at but some of the most common symptoms of AD are memory loss, wandering and getting lost, and difficulty communicating (NIA). People from all races and ethnicities can develop AD (AIM). However, like with every disease, there are disparities in terms of what groups face a higher risk. Based on data from a collection of studies, "African Americans are about two times more likely than white Americans to have Alzheimer's and other dementias" whilst "Hispanics are about one and one-half times more likely than whites to have Alzheimer's and other dementias" (AIM).

The number of worldwide dementia cases is expected to grow at alarming rates in the foreseeable future. IHME researchers at the 2021 Alzheimer's Association International Conference (AAIC) presented findings that estimate dementia cases to triple in the next 30 years, going from "an estimated 57.4 million cases globally in 2019 to an estimated 152.8 million cases in 2050" (Nichols and Vos). In their report, Nichols and Vos acknowledge how the projected increase could largely just be due to a population that is growing and aging (Nichols and Vos). Importantly, at last year's AAIC, Nichols shared how she hopes these numbers will equip "policymakers and decision makers [a more comprehensive understanding of] the expected increases [themselves]…as well as the drivers [for] these increases" while also demonstrating a heightened "need for research focused on the discovery of disease-modifying treatments and effective low-cost interventions for the prevention or delay of dementia onset" (AAIC).

As cases of dementia grow, the urgency to find treatment options for AD patients, and to learn more about dementia in general, will also grow. In turn, more pressure will also be put on

the government to increase funding for neuroscience research, as has been happening for a little over the last ten years. The policy most responsible for significant annual increments in governmental AD research funding is the National Alzheimer's Project Act (NAPA) which was enacted in 2011 (AIM, Bayh). Even with access to tremendous monetary support, science has not been able to determine a comprehensive understanding of what causes AD, much less facilitate the output of treatment options that do anything besides symptom management. While there is definitely a need for AD studies to continue being financed, it is unreasonable for this giant pool of capital to be streamlined to one place, the one place being scientific efforts. Given the inability of science to *guarantee* a meaningful output, the sensible course of action should be to decentralize AD-designated resources (monetary or otherwise) and distribute them more equitably.

Based on my research, I contend that goals for AD in the next ten years should aim to diversify available treatment options for patients and to expand care options for caregivers and families. One area that could be given more attention is the humanities. When mentioning the humanities here, for the sake of this entire paper, I am referring to disciplines like "philosophy, history, literature, art, classics, and music, among others" (SHC). Science champions tend to dismiss these genres and are "eager to write off [humanities] disciplines as "soft," subjective, and therefore inferior to science and its rigorous approach" (Boehnke 1166). Sometimes the most complex or rigorous approach is not the best approach. After all, in biology, the principle of parsimony states that "the most acceptable explanation of an occurrence, phenomenon, or event is the simplest [explanation], involving the fewest entities, assumptions, or changes" (Martin and Hine). Moreover, the humanities should be viewed as a useful tool to "enhance the practice and understanding of science, among scientists and the public" (Boehnke 1166). Instead of viewing

the humanities as a competitor field, it should be viewed as an aid to the same goals science is trying to achieve or the problems it is trying to solve.

Art therapy or music therapy, which employ the techniques of humanistic genres to treat patients, are—as I term them—humanities-based approaches to illness. The result of these therapies differs from what is expected of a medicative treatment but there are worthwhile outcomes, nonetheless. Specifically in the context of AD and other dementias, art therapy has been shown to affect patients by engaging their "attention, [providing] pleasure, and [improving] neuropsychiatric symptoms, social behavior, and self-esteem" (Chancellor et al.). These kinds of impacts are difficult to quantitatively measure but that is where the focus should shift to *qualitative* evaluations. Do these therapies improve the QOL of the patient? Do they improve the QOL of the caregiver(s)? Does it make living and dealing with dementia a little easier? If the answer to any of these questions, after experimenting with a nontraditional (i.e. not intrinsically scientific) treatment approach, is "yes", then it is worth delving deeper into such methods. Expanding what is considered "treatment" and making a variety of options widely available and accessible to AD patients and their families could alleviate some of the daily struggles that people face. This will be especially necessary as the number of communities afflicted by AD and dementia grows and traditional treatment options become more limited.

Alternative Therapies: Music and A Memorable Artist

> As long as a particular disease is treated as an evil, invincible predator, not just a disease, most people with cancer will indeed be demoralized by learning what disease they have.
>
> — Susan Sontag, *Illness as Metaphor*

As soon as my grandmother started experiencing dementia symptoms, she simultaneously began to lose her autonomy. It was as if her independence coiled up and slowly retreated as soon as it felt the presence of the invincible predator, preying upon her mind (Sontag, 7). To add on to the self-inflicted withdrawal, my family started to prevent her from doing certain tasks. In response to the many plates of undercooked chicken and burnt rice, my grandmother was not allowed to cook anymore, something she had done every single day, feeding our entire family, for as long as I could remember. Eventually, there was very little that she *did* do.

While it is logical to prevent AD and dementia patients from engaging in activities that would put them or others in harm's way (i.e. cooking and risking the start of a kitchen fire), I argue that it's important to have an active curation of relationships, activities, spaces, resources that enable and encourage participation, relationship building, and expression. I have found in my analysis of my own lived experience as well as close-readings of medical care practices and literature depicting life with AD that, whether it is intentional or not, AD patients are often excluded from their usual forms of social and relational behaviors and activities that they used to have. They are not invited to the table, never mind the party. Sometimes, this is because they ostracize themselves but it can be argued that others also purposefully omit them from social situations or activities. People that do not, directly or indirectly, know someone suffering from AD might not understand what it means to be around someone with cognitive impairment and are more likely to adopt false understandings of what dementia patients can or cannot do and

how they can or cannot participate. Thus, a common pattern I have encountered in the materials I have analyzed is to not include AD patients in activities, conversations, and group events. Normatively abled people cannot easily understand them and are inclined to be weirded out by them, react to them with disgust, or simply ignore them. Yet, the default othering of people with AD is really a missed opportunity to make living with AD as positive of an experience as possible.

Ingunn Moser is a STS studies writer that has explored dementia care at great length. One way that Moser has looked at dementia care is through "modes of ordering", an idea she extrapolated from John Law's *Organising Modernity: Social Ordering and Social Theory* (Moser 707). Moser uses two main "modes of ordering to make an argument about politics and normativity in STS", the first being a somatizicing order which generally has "to do with the soma, a matter of biology" (Moser 708, 711). This mode is analogous to the idea of "Science as the Holy Grail" that I have discussed in detail in earlier sections of this paper. The second mode is the relational order that works "to counteract or at least postpone [the] process of disconnection" that dementia patients experience (Moser 716). Moser describes how "dementia presents itself as a growing mismatch and problem with relations between the patient, the daily environment and fellow beings", which is what most people struggle to understand is what happens as neurocognitive impairment progresses (Moser 714). This failure to comprehend what is actually happening in AD stirs up the fear that is associated with dementia, otherwise known as what I call "The Dread".

Similarly to the case that I am trying to make here, Moser acknowledges how the "relational approach does not deny the reality and objectivity of [dementia] but demonstrates a different way of acting upon life and shaping ways of living and dying with dementia—within

the medical world" (Moser 716). Thus, the relational approach presents an opportunity to introduce nontraditional methods of dealing with dementia patients. In her paper, Moser uses examples of Mrs. Olsen, a Norwegian nursing home dementia patient in her eighties, to really make her case about the benefits of relational ordering (Moser 708). Moser shares how Mrs. Olsen's caretaker has incorporated music therapy techniques into her daily care routine "to create a channel for contact, connection, and communication" (Moser 713). As is true for many AD patients, Mrs. Olsen struggles to speak and when she is able to get words out, they aren't necessarily coherent (Moser 705). As such, music therapy in this scenario serves as an important tool to "open up access to the person's life history and [to] build connections to her life and her self… through emotion, experience, and memory embedded in wider, more distributed and complex forms" (Moser 713). This kind of connection is something that could not be achieved in a somatizicing approach of care because it is not scientific in nature; it is humanistic. I understand the relational approach of care to put forth an interactive framework, centered around bridging differences in ability. The reciprocity of the relational approach gives AD patients the opportunity to also be active agents in their interactions or, more generally, in the social world. By sanctioning their choices in music and granting the space to sing along if they choose to, music therapy acknowledges AD patients' social agency. Likewise, having the opportunity to depict themselves and their environment through art therapy allows people with AD to form an engagement with and embody the world as they see fit.

A notable instance of someone who integrated some version of art therapy into their own experience living with AD is William Utermohlen. Utermohlen was born in Philadelphia in 1933 where he would end up attending the Pennsylvania Academy of Fine Arts to study art (King 64). He continued his studies in the late 1950s at the Ruskin School of Art in Oxford, England, which

led to him settling in London, where he spent the rest of his life until his passing on March 21, 2007 (Boïcos and Norback). Utermohlen's art consisted of "portraits, still lives, and drawings from the model" but was thematically diverse, inspired by and changing synergistically with the different stages and time periods of his life (Boïcos and Norback).

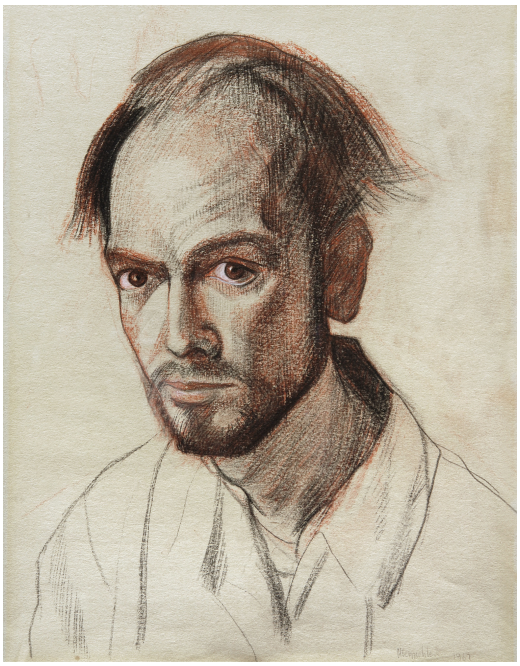


Fig 3. William Utermohlen; "Self Portrait", 1967, http://boicosfinearts.com/exhibitions/william-utermohlen-a-persistence.html; mixed media on paper.

Utermohlen's life changed in 1995, at the age of 62, when he was diagnosed with AD (King 64). Still, he remained active and made art until he couldn't anymore. Utermohlen produced his last pencil drawings from 2000-2002, five years prior to his death at 74 years old (Boïcos and Norback). While Utermohlen did not engage in conventional art therapy, his dedication to his art and willingness to preoccupy himself, for over ten years after his diagnosis, is a testament to the value of artistic expression in AD patients. Typically, AD patients live on for "an average of four to eight years after [an AD diagnosis]" (Alzheimer's Association 723).

Utermohlen's lifespan exceeded that of the average AD patient and, although it might be frivolous to attribute his longevity to artistic expression alone, it wouldn't be illogical to assume that perhaps his artistic creations were a contributing factor to his relatively long life.

Fig 4. William Utermohlen; "Self Portrait - Two Sculls", 1995, http://boicosfinearts.com/exhibitions/william-utermohlen-a-persistence.html; pencil on paper.

Utermohlen's ability to produce more than 20 self portraits (from what is posted on the Chris Boïcos Fine Arts website) over the course of his illness is not only a testimony to his own initiative but it is a look into the kind of support system that he had around him at that time. His wife, Patricia Utermohlen, shared how he would show each completed self portrait to his nurse, who would proceed to visit the studio and photograph every new work, because he believed that "William's efforts were helping to increase the understanding of the deeply psychological and traumatic aspects of the disease" (Bahadur). To continue creating, Utermohlen needed to be encouraged, motivated, and somewhat inspired, which are all factors largely influenced by the

kind of people one has in their surroundings. AD patients are undoubtedly difficult to deal with. They can behave in unexpected and, sometimes, violent ways. People that are intolerant or unsympathetic to what AD patients are going through might consider their "bad" or atypical behavior as reason to exclude them or prohibit them from partaking in certain activities. On that account, it is crucial that their support network is made up of people that already are, or are willing to learn how to be, patient, compassionate, inclusive, and uplifting. While perfection (i.e. never losing patience) is an unrealistic expectation, it is important that AD patients have access to a support network that really tries their best to show them love and make their environment a positive place to be in.

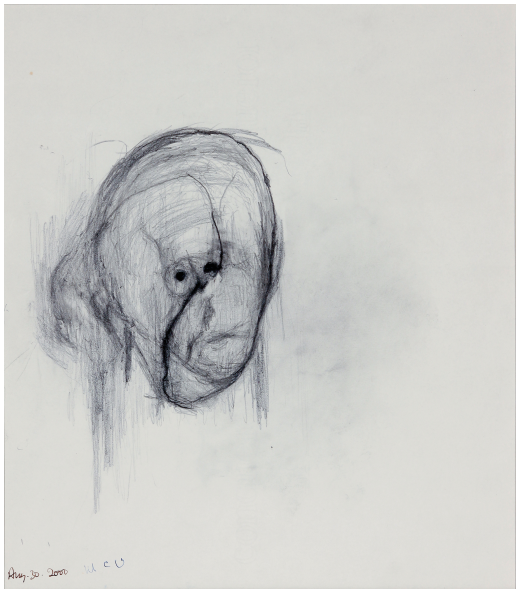


Fig 5. William Utermohlen; "Self Portrait - Head I", 2000, http://boicosfinearts.com/exhibitions/william-utermohlen-a-persistence.html; pencil on paper.

The work of William Utermohlen is representative of more than just his own desire to remain useful and the community of people around him that made his work possible. His art acts as a window, looking into the inner workings of his mind as AD dominated it. Evidence of AD is "apparent in the shifting perceptions of space, objects, and people" (Boïcos and Norback). As the

images progress, the location of his head on the page starts to migrate off-center (see fig. 5). Compared to the self-portraits he made preceding his AD diagnosis, the way Utermohlen draws his skull changes in length (see fig. 3). The skull starts to appear more elongated, as if it was growing or the weight was shifting towards the posterior or dorsal side of the body (see fig. 4). Additionally, more lines are drawn in places that form ridges in the skull that were not previously depicted (see fig. 4 and fig. 5).

One of the more obvious modifications is the loss of facial feature definition as time progresses, which could be an indication of "a progressive loss of identity or sense of self" (see fig. 5, King 65). After five years of AD wreaking havoc upstairs, Utermohlen's self-portraits start to lack eyes and eyebrows (see fig. 5). The facial features that did make it onto the face—such as the ear, nose, and mouth—have drastically lost precision and look nothing like the extraordinarily skillful portraits he had composed in the past (see fig. 5). Rather, they appear more disfigured and blob-like, and are not aligned realistically on the face (see fig. 5). Utermohlen's portrait drastically deviates from classic representations of what a face "should" look like which can evoke feelings of unease, disgust, or repulsion in viewers. Nevertheless, this is not surprising due to "the loss of facial recognition that is often [a symptom] of AD" (King 65). In the ways described above, Uterlmohlen's art becomes a communication tool for the many symptoms he is experiencing but cannot articulate. It allows him to be transparent about what he is going through with the people around him without having to dig through his jumbled up thoughts, on a quest for the right words.

The effort required to incorporate art therapy into a dementia patient's routine is worthwhile. Giving patients an opportunity to spend time with their imagination and make something tangible is as a way of returning some of their autonomy back to them. Art therapy

tasks give dementia patients authority over an unspecified deliverable and “can help reduce the feelings of isolation and loneliness that accompany AD” (King 66). In theory, art supplies and proper supervision are all that would be vital to the execution of an art therapy session for AD patients. Compared to the cost of the research that is fundamental to generate a pill that results in similar effects (i.e. reduced feelings of isolation and loneliness), art therapy is a way more cost and time-effective means of improving the QOL of AD patients.

Tangles

Tangles: A Story About Alzheimer's, My Mother, and Me is exactly what the title describes. Sarah Leavitt introduces the reader to her mother, Midge, and tells us the story of her life from beginning to end, primarily focusing on life after the AD diagnosis. Like most people with loved ones affected by AD and dementia, Leavitt loved her mother and watching her mother's decline, even if from afar, was painful. Despite the striking depictions of grief and sadness that Leavitt accurately captures in her work through illustrations and anecdotes, reading her graphic novel was a comforting experience.

AD representation in something other than a scientific journal or the AA website is sometimes hard to come by. Leavitt's honesty and willingness to share even the worst of her thoughts while helping to care for her mom with AD is refreshing and relatable. The personable nature of a story from a daughter who understands the deep pain associated with losing a loved one to dementia, otherwise known as an AD memoir, is reimagined in a visual-heavy format. Not only is reading this book a necessary experience that all AD-affected-families and caretakers should have access to, but it is a great resource for people unaffected by dementia to actually envision what it might be like. There is so much healing potential in artistic depictions of horrendous mind conditions that are otherwise "invisible", unlike a fractured bone or a skin rash, for instance. Of course, AD is not completely invisible as it is very much apparent in the behavior of the patient. However, there is an invisibility aspect in the care that AD demands from caregivers. Being represented in art and knowing that one's experience is not an isolated one allows for a transparency that is alleviating and, hopefully, can make peoples' experience in caring for a loved one less burdensome.

Fig 6. Sarah Leavitt; "Midge suspects she "[has] Alzheimer's." *Tangles: A Story About Alzheimer's, My Mother, and Me*, 2012, graphic novel panel.

Leavitt shares many anecdotes with us but one that particularly caught my attention was of the time that she and her girlfriend visited her parents in "Sunny Mexico" after Midge revealed that she possibly has Alzheimer's (see fig. 6). The contrast between the panels of their visit to "Sunny Mexico" and the singular panel of Midge saying "I have Alzheimer's" is quite compelling (Leavitt 25, 28-29). The revelation that Midge probably has AD is one that is hard to accept for all members involved in that conversation, including Midge. At this time, she is not so far along in the progression of her disease which means that she is aware of the ways in which she is changing. The way that Leavitt has drawn her face in this panel with a dismal expression and bags under her eyes is representative of that hard pill to swallow and the intense worry she may be feeling (Leavitt 25). The all-black background is symbolic of the loneliness that Midge likely feels at the beginning of her cognitive impairment journey and how the realization of what is happening to her can feel all-consuming (Leavitt 25).

Arguably, the very beginning of the disease is one of the hardest times in a patient's life *because* of the occasional awareness they have of what is happening to them. Patients might be

cognizant of the changes they are going through but they also have the knowledge that there is absolutely nothing they can do to change their inevitable fate. Moreover, this time of severe hopelessness is accompanied by the awareness of how their family is responding. The unfortunate truth is that families do not usually have the best responses to the strange behavior that patients experience during the onset of AD symptoms. Families might be angry, frustrated, or confused, when their loved ones start acting unlike they have ever acted before. These external responses that the patient cannot control only heightens the deep fear, solitude, and suffering that the patient is already going through.

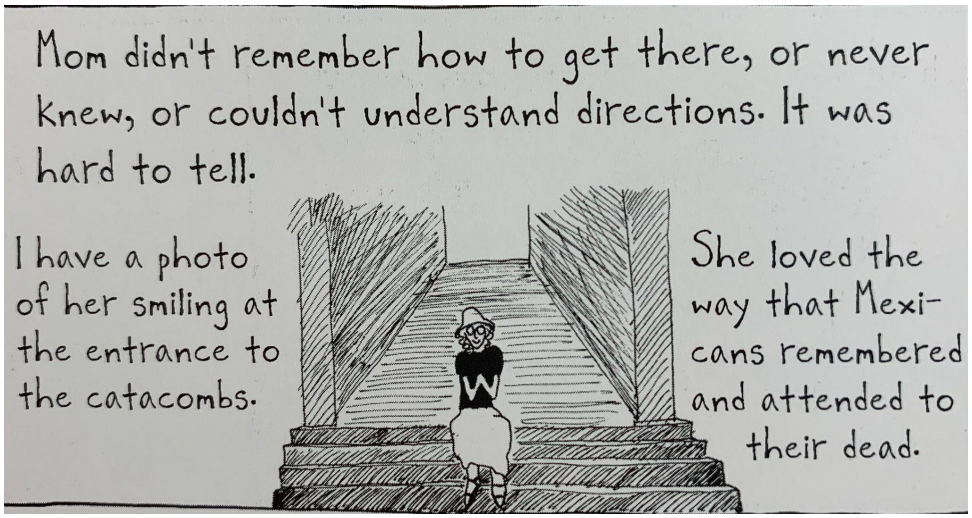


Fig 7. Sarah Leavitt; "Midge sits contently on some stairs, reflecting on her Mexico trip." *Tangles: A Story About Alzheimer's, My Mother, and Me*, 2012, graphic novel panel.

The disclosure of Midge's possible AD diagnosis is immediately followed by the family's trip to Oaxaca, Mexico which is made up of several panels where Midge appears somewhat joyful (Leavitt 28-29). The black and white illustrations contrast the vivid descriptions of the family's activities while on vacation. The expressions of contentedness on Midge's face symbolizes her attempt to make the best of her situation and to try and enjoy herself despite the AD related obstacles that have now begun to present themselves. The last panel on page 29

closes with the powerful sentence "[Midge] loved the way that Mexicans remembered and attended to their dead" which interestingly distinguishes the way that departed loved ones are treated in Mexican culture compared to American culture, for instance (see fig. 7).

Perhaps unintentionally, Leavitt alludes to how there are differences in the way other cultures treat their elderly. In American culture, it is common for elderly folks to stay living by themselves until it becomes unsafe for them to do so. At that point, it is acceptable for families to help elders move into a nursing home or assisted living facility. On the other hand, in Latino culture, living in an establishment, such as the ones listed above, is far from the norm. For Latino elderly, it is customary to go live with their family after they cannot continue living on their own. Consequently, a family member(s) generally takes on the responsibility of being a designated caregiver and is entrusted with the wellbeing and safety of the elder.

More often than not, this kind of care is informal, meaning it is "unpaid help from family and friends" (Weiss et al. 146). In a 2004 study looking at discrepancies in the receipt of informal care by disabled people aged 70 or older in the U.S., researchers found "a significant association between informal home care and ethnic group, with 44.3% of Latinos receiving informal care, compared with 33.9% of African Americans and 24.6% of non-Hispanic whites ($P<.001$)" (Weiss et al. 146). Marginalized communities, like Latinos, are "at [a] higher risk for poor health outcomes due to higher rates of poverty and lower rates of health insurance coverage than non-Hispanic Whites" (Weiss et al. 146). It only makes sense to infer that marginalized communities are also less likely to be able to afford formal care options for their elders. On average, families that pay for formal care (i.e. paid family caregivers) incur an average of $7,242 annual out-of-pocket expenses (Skufca and Rainville). Leavitt implicitly points out how Latinos might attend to their elders more closely than other groups but it is important to consider the

many reasons why that may be. “Cultural values and norms regarding responsibilities toward elders” contribute substantially to how Latino families decide to care for their loved ones but “level of disability and disease and socioeconomic status” also present barriers to the options that are available to marginalized communities (Weiss et al. 148). Thinking about alternative care options could offer opportunities to—at least partially—circumvent the social and economic obstacles that marginalized communities disproportionately face.

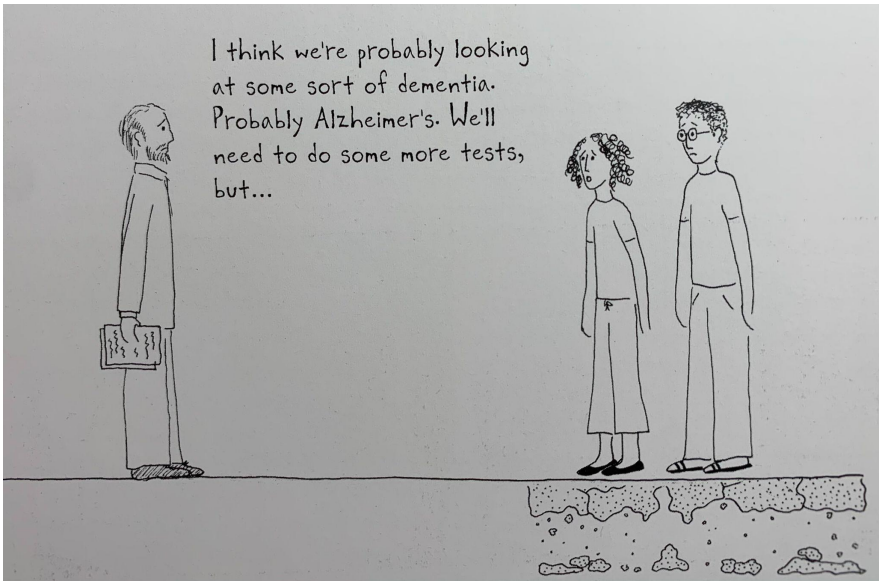


Fig 8. Sarah Leavitt; “The ground crumbles underneath Sarah and Rob as the doctor confirms Midge’s diagnosis.” *Tangles: A Story About Alzheimer’s, My Mother, and Me*, 2012, graphic novel panel.

After the family returns from Mexico, they end up visiting the neurologist. Following a series of questions and examinations, the doctor reaches a diagnosis: Alzheimer’s. Upon hearing those words, Leavitt illustrates the ground literally crumbling underneath her and her dad (see fig. 8). Their two bodies are positioned ever so slightly leaning forward in disbelief (Leavitt 37). Their slanted eyebrows convey the heartbreak they are feeling after hearing such dismal news (Leavitt 37). In her depiction of Midge sitting in a chair, enduring a series of seemingly easy

questions being thrown at her, Leavitt denounces the insufficient and almost arbitrary tasks that are completed to arrive at an AD diagnosis (see fig. 9). The fearful expression on Midge's face signals how the questions are actually challenging for her and how she feels pressure to answer them accurately (see fig. 9). Leavitt also includes a panel of herself with an angry expression on her face, imparting the frustration she felt while listening to the neurologist interrogate her parents (Leavitt 37).

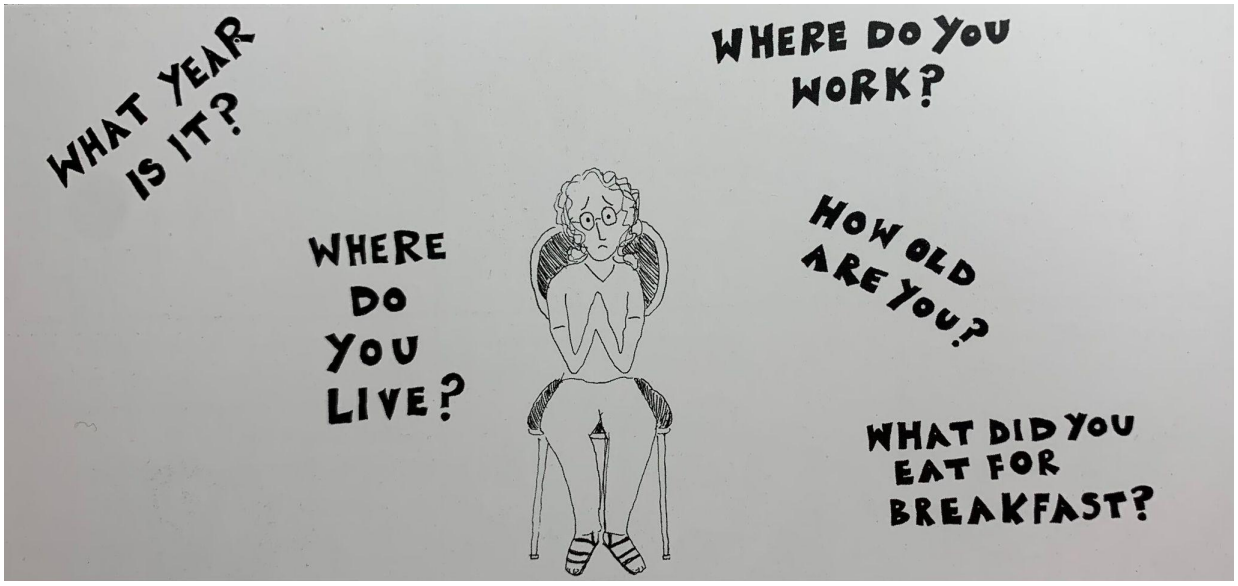


Fig 9. Sarah Leavitt; "Midge faces a series of questions for her neurological exam." *Tangles: A Story About Alzheimer's, My Mother, and Me*, 2012, graphic novel panel.

There is no doubt that diagnoses are often life changing and grief inducing, for both patients and their families. No one wants to accept the inevitable decline of their loved ones. However, acceptance is also influenced and made more difficult by the nature of *how* these neurodegenerative illnesses are identified. Some of the methods used by medical professionals to arrive at a diagnosis can be intimidating for patients. Us readers get the impression that the entire experience feels very impersonal and insensitive.

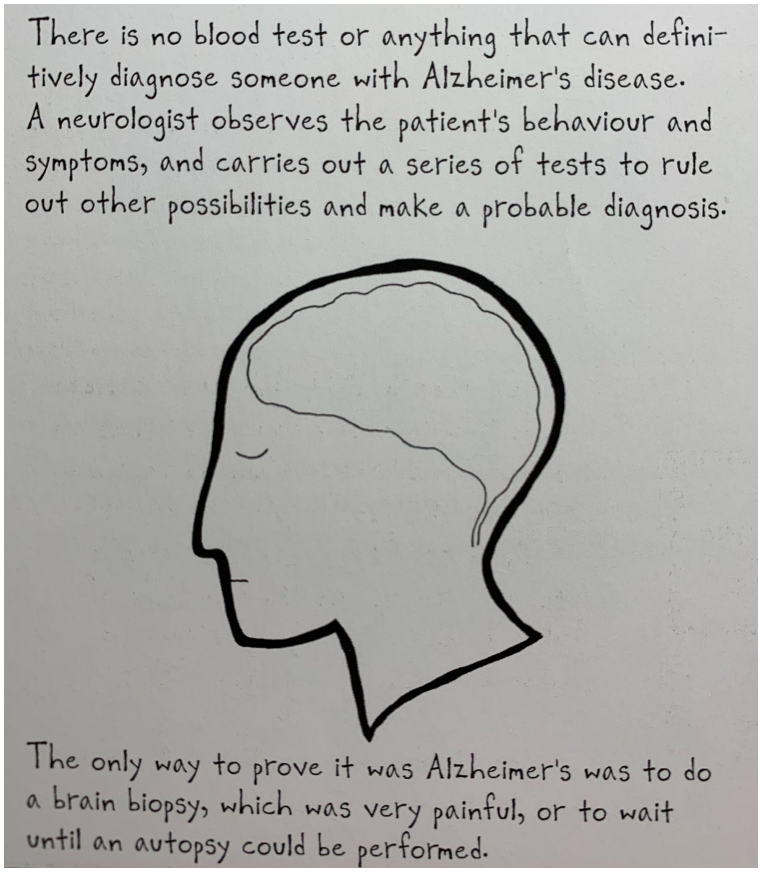


Fig 10. Sarah Leavitt; "Leavitt describes how an AD patient gets diagnosed." *Tangles: A Story About Alzheimer's, My Mother, and Me*, 2012, graphic novel panel.

Leavitt gives a relatively in-depth account of what exactly an AD diagnosis is based on. The panel in which she includes this explanation is one of the wordiest panels in the entire graphic novel, up until this point. The simple picture of an empty human head surrounded by two mini-paragraphs is difficult to ignore (see fig. 10). The rudimentary style of the illustration makes it appear foreign, as if to communicate how little is actually known about the human brain (see fig. 10). Leavitt points out the lack of "definitive" AD diagnostic tools (Leavitt 40). Leavitt points out that diagnosis is based primarily on observations of "behavior and symptoms" (Leavitt 40). Even when a diagnosis is reached, it is a "probable diagnosis", nothing is ever certain (Leavitt 40).

AD is not an easy conclusion to arrive at. There is no sample that can be taken, within reason. There are no numbers, graphs, or lab results that give patients and their families a "for sure" answer, which of course adds on to the inherently difficult work of learning to accept. When one is battling the likelihood that their loved one has AD, it is easy to lean into the idea that observations can be subjective. While neurologists are, obviously, trained professionals whose observations are meant to be credible, they are still people and people can be wrong. At the beginning, holding on to the chance that a neurologist's diagnosis could be inaccurate is one way that dementia patients' families hold on to hope.

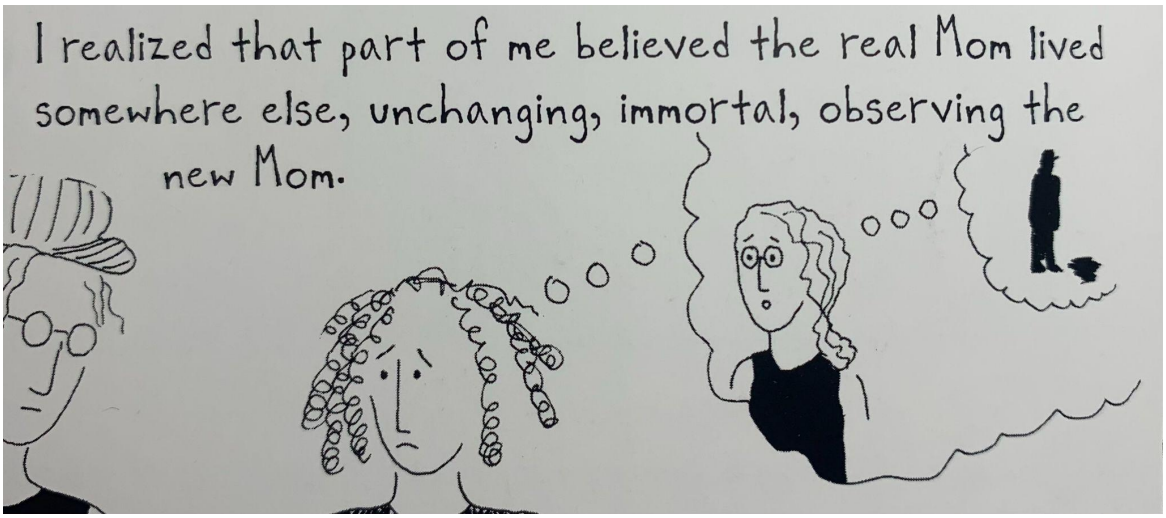


Fig 11. Sarah Leavitt; "Leavitt secretly hopes her 'real' Mom is still around." *Tangles: A Story About Alzheimer's, My Mother, and Me*, 2012, graphic novel panel.

There is a phrase in Spanish that my mom always tells me—"*La esperanza es lo último que se pierde*"—which translates to: "Hope is the last thing you lose." Sometimes, the desire to hold on to hope never leaves. After all, "hope *is* the thing with feathers" and is much more lightweight than logic (Dickinson). Even after years of my grandmother having dementia, deep down inside, I hope there is an immortal sliver of her, somewhere in her body. Sometimes, I *believe* she is still in there. I have fooled myself into thinking her soul is hiding, and is only

afraid to come out. Sometimes, the story changes and I fool myself into thinking she is trapped but will escape one day. Whatever version I have somehow tricked myself into believing is temporarily comforting.

Leavitt is remarkably successful at describing the necessary internal narratives that one might imagine to cope with the truth of their loved ones' irredeemable state. The stark portrayal of Leavitt directly facing her "fake mom" with a look of fear or disappointment on her face embodies how emotionally demanding it can be to confront reality (see fig. 11). The look of appall on "real" Midge's face in Leavitt's dream bubble speaks to how much Midge has been changed by AD and how the "real" Midge would disapprove of her own behavior (see fig. 11). The contrast between Leavitt's "fake mom" and "real mom" is also daunting (Leavitt 94). "Fake mom" is pictured as having no eyes, no eyebrows, and seemingly incapable of making facial expressions or having emotions (see fig. 11). "Real mom", on the other hand, has eyes and eyebrows and is able to sympathize with the predicament at hand (see fig. 11).

Leavitt's ability to encapsulate the very real, and relatable, feelings and moments that made up her mother's journey with AD is a true gift to her readers. Her authenticity, and ability to articulate the instances that are not usually easy to describe, makes reading *Tangles* a fulfilling experience. Not only does Leavitt shed light on the less spoken-about, not-so-fun realities that accompany taking care of someone with AD, but she incorporates the nonlinear disposition of the course, which is not always well understood. Leavitt's inclusion of the joyful and funny moments that occur when caring for an AD patient aids in her construction of a well-rounded and forthright personal account of her experience.

To properly contextualize *Tangles*, recognizing its status as an AD memoir is critical. AD memoirs are characterized by "the witness's yearning to retrieve a coherent sense of the past"

(Simon 8). In *Tangles*, Midge is "not [offered her] own narrative of what [she was] experiencing, unless [the] narrative [was] mediated by the witness writer", which in this case is Leavitt herself (Simon 8). *Tangles* is undoubtedly from the perspective of Leavitt but unlike other AD memoirs that are inconsiderate of the AD sufferer's point of view, Leavitt does draw attention to how Midge could be feeling. She touches on topics regarding Midge's personal losses: senses, abilities, privacy, and appetite, amongst others. Either way, my intent is not to argue for *Tangles*' superiority in comparison to other AD memoirs but to demonstrate its value in depicting the experience of AD patients and families, outweighing its contribution to the voicelessness of AD patients in literature (Simon 8). *Tangles* takes steps towards representing the struggle and making it possible for caregivers and families to see themselves in a narrative about someone else going through something similar.

Conclusion

Through opportunities for patients to engage in cultural productions and humanities-based approaches of managing AD and dementia, the QOL for patients, caregivers, and families, has a strong potential to improve. Alternative therapies and storytelling are avenues through which the sadness involved with caring for a loved one diagnosed with AD may be alleviated. Currently, there is a questionable trust in science to deliver outcomes that lessen the burden of the ongoing battle against AD. Moving forward, overreliance on time-consuming and expensive research will not be sustainable, imploring the need to explore and expand the care options available to AD patients.

As the number of AD patients continues to grow annually, thinking creatively about care options will be fundamental to managing the cognitive impairment crisis. Formal care options are expensive and, therefore, inaccessible to many. Solutions within the humanities can present more affordable options for struggling families. Furthermore, broadening societal views on what is considered treatment and what is not can change the scope of healthcare. To clarify, the scope of healthcare is limited by who can administer care. If we change how we think about care, then we must reexamine: who is qualified to distribute what kind of care? The politics of care with relation to dementia will be affected by these broader questions addressing the scope of healthcare and its delivery but these changes will not be confined to just one type of illness. Other categories of illness will be impacted and this will ultimately lead to systemic changes in medicine as a whole.

To compensate for the speed of science, or lack thereof, alternative treatment and care options will further demonstrate their worth. Science's failure to provide outcomes will force society to ponder questions about techno-optimism and why it is so deep-rooted in the first place.

Simultaneously, social and political movements promoting distrust in the scientific community, especially over the last few years, will only fuel the skepticism. Perhaps, the dire need to regain the trust of society (i.e. whom science serves) will compel the scientific community to reevaluate the bureaucratic processes in place that unnecessarily elongate investigations.

Since humanities-based treatments are not taken seriously, there is not much in the literature about the real impacts they have on patients. This lack of evidence is also hindered by the need to measure data quantitatively. Implementation of alternative methods will call for future studies to explore the qualitative results of these approaches on patients' lives. Additionally, considerations need to be made about how to effectively incorporate alternative care options into formal care settings, given how, as of now, they are only typically integrated into informal care situations.

People that have a say over the lives of AD patients, such as their caregivers and families, need to review what their priorities of care are. When thinking about care, it is not uncommon to only mull over ways to subdue symptoms. Prioritization of symptom management in patients with incurable diseases is pointless. Symptoms will never be completely "managed". That is assuming control over the disease, which in reality nobody will ever have. Instead, more emphasis should be placed on QOL. How can we make living with AD a better experience? How do we value the life of AD patients? Are we caring for them because it is a duty we have taken on or because we *want* to? How can we appreciate their contribution to our lives and dedicate efforts towards improving their living conditions? Reframing our answers to these questions will facilitate changes in our mindset towards patients who need help to live.

Music is one modality through which mutual engagement with AD patients can be organized. While spending time with my grandmother, I have searched up Cuban music from the

1950s and 60s and every so often, a song will play that will inspire her to sing along. Sometimes she will not necessarily make a sound but she will mouth the words. I will go ahead and try another song to see what other responses I can provoke. Over time, I have curated a playlist of some songs that I know she can identify and enjoy. These songs serve as a meeting space for my grandmother and I. They enable her to be present with me, for us to be in relation with each other, and to share quality time together. Finding other modalities that also help construct meeting spaces for AD patients and other people to connect will be vital in the battle against AD moving forward.

Spanish cartoonist, Paco Roca, is another person who is continuing the work of AD representation through a graphic narrative. In the 2008 graphic novel titled *Arrugas*, Roca provides a fictional story, though based on real people and real events, about a man named Emilio who gets diagnosed with AD and his son chooses "to move him into a transitional care facility" (Fraser 139). Like *Tangles*, *Arrugas* affords readers a space to appreciate "the unique aesthetic aspects of visual narrative [which] allow us to understand the material experience of [AD] within a collective and social framework that folds the clinical back into the non-clinical, everyday, social experience of cognitive disability" (Fraser 169). *Tangles* and *Arrugas* are both examples of the power in the visual modality of storytelling (Fraser 169). Storytelling has healing properties and is worth considering when it comes to making resources available to AD patients and families.

Fig 12. Benjamin Fraser; “Emilio’s point of view over a meal; panels from *Arrugas* by Paco Roca” *Sequencing Alzheimer’s Dementia: Paco Roca’s Graphic Novel Arrugas (Wrinkles) (2008)*, 2018, graphic novel panels.

Hallucinations are part of the long list of dementia symptoms. My grandma is always talking to someone else. My words don’t necessarily get through to her because she is preoccupied with her own conversations. She is essentially living in a different universe and having differing experiences of the world. Watching TV is one way for her to be grounded in the same reality as I. When she is in front of the TV, that’s when she reacts—colorful moving images, cartoons, and animated movies capture her attention. She will laugh really hard, or exclaim, or say something. Our planes of reality intersect here—when we are both watching TV. There is a moment where it feels like we are both experiencing and reacting to the same thing, together. In this way, visual modalities evoke a response that words cannot. TV and other visual productions offer a way for my grandma and I to meet, to exist in unison, and share an experience.

Visual modalities are another means of generating connections. The visual creates a space for "those who seem unable to tell stories" to consciously or unconsciously immerse themselves in an imaginary that others have a stake in (Fraser 169). Moreover, visual productions traverse cultural barriers and leave room for interpretation of all viewers. Even if *Arrugas* was not translated into other languages (i.e. the English translation, *Wrinkles*), I am confident in its ability to reach people globally just based on the universal messages communicated by the illustrations. Albeit, the uniqueness of the graphic novel format stems from its marriage of the visual with the narrative. Narratives about AD in a variety of languages are essential to increase accessibility of relational and culturally diverse approaches to care. The significance of *Arrugas* being made available in other languages and being successful in multiple parts of the world "confirms that Spain is not alone in facing the issues raised by an increasingly aging population: the matter of Alzheimer's disease has global resonance" (Fraser 141).

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