

Article

Familiar Strangers in the Shrouded Forest: Stigma, Representation and Alzheimer's Disease in *Always*

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Abstract: While literature and popular culture have sought to understand Alzheimer's Disease (AD) in terms framed by the loss of social relationships and the strain caregivers face, this arrangement articulates AD as "being lost", a fragmentation of temporal experience, or as irrationality punctuated by moments of self-awareness (which often operate to dehumanize those with AD). This analysis seeks, as Stefan Merrill Block puts it, to "stop looking for the lost person" in our encounter with AD. As a contemporary case study, the interactive experience *Always* functions as a critical intervention by not prizing moments of clarity as narrative catharsis (which literature and popular culture tend to do in the form of what is known as the "love miracle"). Instead, it serves as an important gesture toward destabilizing these practices and bridging the gap between the representation of AD and its realities. Rather than acting as a simulator of AD, *Always* is an abstract piece that, through design and game mechanics, opens a space for users to consider the implications of having their senses destabilized. As a result, this analysis considers how design addresses issues of social stigma, representation, storytelling and navigability.

Keywords: Alzheimer; dementia; memory; videogames; design; Stigma



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1. Introduction

"Strewn before me, across dust and scratch adorned shelves lay the history of the ancients, the myths of Byzantium, and such esoterics as had hardly a chance to be remembered before they were cast into words and forgotten". (*Always* 2021)

"To have an identity is to know who one is, in cognition and feeling. It means having a sense of continuity with the past; and hence a 'narrative', a story to present to others" (Kitwood 1997, p. 43)

Though Alzheimer's Disease (AD) is a relatively well-known form of dementia, much of our understanding of it has been formed through popular culture. Released in 2021, the interactive experience *Always* (2021, video documentation at <https://tinyurl.com/yc5bvhyc>, accessed on 11 October 2023) is a first-person exploration game for PC that uses a keyboard and mouse, or an attached controller, to allow users to navigate around a deeply affective space, replete with spatially located sound and circular narrative in order to offer a sense of what it feels like to have one's perceptual systems undercut. Rather than serving as a direct stand-in for the experience of dementia and AD, the first-person perspective and adaptive design of *Always* raise questions about the very nature of our reliance upon experience and our senses. More than a theoretical exploration, it is a personal project born from my own personal experiences as both the designer of the experience and a family member of someone experiencing AD. Rather than argue that there is a single "way" to experience or view AD, the purpose of this exercise (both the experience of *Always* and this article) is to problematize the monolithic notions we have about the disease and its implications and open up new ways of thinking about what it means to experience AD (as a patient, family member and/or caregiver).

I spent much of my adult life watching my grandmother struggle through the day-to-day experience of AD. Sitting next to my grandmother, watching her hug onto a large stuffed animal, I was struck by the differences between the woman I knew during my years running around her home and the one who sat before me. Now, in her late 90s, she was as hearty physically as I could ever remember her. She always told my mother that she would “live to be 100”, and though she fought through two bouts of COVID-19 over a year, one would have been hard-pressed to argue with her. For the past few decades, she lived almost completely “in the moment”, with each instance of affect acting as an instantaneous response to a given sound, a stranger’s smile (as we are all welcomed strangers now), or a compassionate tug on her hand from her greatgrandchildren. Though it is tempting to suggest that she is no longer “there”, someone was still sitting next to me.

There is a great tendency to characterize AD as an attack on the “self”, that “a person loses his or her memories, relationships, and identity, presumably his or her very self or personhood is lost” (Selberg 2015, p. 475). And yet, such a position misunderstands the very nature of the disease and what it means for those impacted by it. To think that our personhood, and the concomitant dignity that comes with it, is somehow tethered to our memories and social relationships reinforces the kinds of dehumanization and depersonalization that Kitwood (2012, p. 90) notes are the result of both our innate fears of frailty and dependence, as well as those of mental instability. And yet, she still sits there; a testament to the kinds of human bonds that extend beyond memory and verbal communication. Not too many weeks before she passed away at age ninety-nine, she told my mother that she loved her. Whether this was some emotional response, the mimicry of a witnessed moment, or the cognizant firing of synapses in recollection, the earthly connection between us persists even as disease carves away the memories that took a lifetime to build.

Seen through this lens, AD takes something away but returns something in its place. That is not to diminish the true cruelty of the disease, as its “relentlessly progressive” nature strips away aspects of the person whom you love piece by piece (Castellani et al. 2010, p. 486). What is lost in our analysis, as families, friends, medical professionals and researchers, are the bricks left behind, reconstituted into the person who remains. Though it is easy to find examples of caregivers and loved ones that capture their stories and reflections on the experience of supporting someone with AD, the experience of living with the disease is a much more complicated thing to communicate and reflect upon (though some have tried). More than “forgetting”, AD sets about reconfiguring you in ways that, though they can occur without you realizing, leave their initial telltale signs in the questions and stories already answered and told, brought up again and again. My grandmother became a master of hiding the symptoms, clinging to her independence. At times, she lashed out in ways that seemed illogical, and yet, looking back, it is easy to see that she was afraid; uncertain of what to do as her world was changing and holding onto what familiarity remained in her life.

As with many family members of those with AD, my understanding of the disease was largely framed by its representation in media. Much like researcher Martina Zimmerman (2017), whose own face-to-face encounter with AD in daily life was markedly different from what her research had prepared her for, I had largely been fed on “medic-scientific dementia discourse” that hardly prepared me for what AD meant. Importantly, “cognitive disabilities [...] have tended to remain disproportionately unseen” (Fraser 2018, p. 29), which ultimately means that those rare representations that I had come across tended to have an even greater impact. Mass-mediated popular culture, particularly in the United States and Europe, has sought to grapple with and represent dementia and AD in terms often framed by the loss of social relationships and the strain upon caregivers in the face of said loss. Films such as *Away from Her* (Polley 2007) and *The Notebook* (Cassavetes 2004), even the comedic drama *The Savages* (Jenkins 2007), enunciate the loss of memory through those “left behind”. Though useful as exemplars of a kind of external representation of dementia and AD, the focus on caregivers and loved ones tends toward a narrative

and visual aesthetic arrangement that prizes the stability of memory and continuity of relationships, oft symbolized through watershed moments of lucidity. Other examples engage with a first-person perspective of AD meant to articulate the fragmentation resultant of the disease. For example, Lisa Genova's *Still Alice*—first published (Genova 2009) then later adapted into a film (Glatzer and Westmoreland 2014) of the same name—tells the story of a Harvard professor who, once diagnosed with early-onset AD, struggles to maintain the connection to who she once was, both for her family and herself. Samantha Harvey's novel *The Wilderness* (Harvey 2010) tells the story of an architect nearing retirement whose own narration unravels in entropic strands as the disease progresses. Even Phyllida Lloyd's biopic of Margaret Thatcher, *The Iron Lady* (Lloyd 2011), offers some insight into the perceived experience of dementia and AD, characterized by jarring shifts in and out of lucidity.

Within this corpus, Stefan Merrill Block points out there is a tendency for the representation of AD to focus itself through the “sentimental trope” of coming to grips with some “repressed or unacknowledged truth that must come before acceptance is possible” (Block 2014). Resolution, though a reliable staple of act-based narrative, offers the kinds of stabilization that hardly capture the actualities of AD. Such representational practices articulate dementia and AD as “being lost”, a fragmentation of temporal experience, or even as the irrationality punctuated by moments of self-awareness. This seems to prize the traumatic moments that, while they no doubt delineate the key phases of the disease for caretakers and loved ones, are not what characterize the disease for those with AD. For my grandmother, the moment she got lost driving and had to pull over and ask someone to help her find her way home was a clear demarcation point for the progression of her disease. It meant that she could not hide the symptoms anymore, that she could no longer drive, and it ushered in the clear recognition for those around her that she needed help. Yet, I recall sitting with her as she voiced her frustration with having her car (and by proxy, her independence) “taken away”. It was not the fear of being lost, or the humiliation of needing to be picked up by her daughter and driven home, that stuck with her—it was the affective confusion of not understanding why she should have to lose her freedom in the first place.

Much of the representation of dementia and AD remains tied to “cognitive symptoms and disengaged behavior”, yet at the same time, “agitated and combative behaviors” are kept to a minimum (Gerritsen et al. 2014, p. 279). Dementia and AD are often associated with agitated and sometimes violent behaviors due to environmental factors and frustration due to confusion and physical discomfort, a phenomenon that tends to get worse as the disease progresses (NIH 2017). Yet, narratives around AD tend to minimize this for a range of reasons (not least of which is the degree to which such behaviors may make it difficult for audiences to identify the characters who have AD). This romanticization relies upon a simplification of the experience of AD and its treatment that dangles in front of the viewer a carrot of the potential for complete lucidity, referred to as the “love miracle” (Swinnen 2012, p. 309). What the “love miracle” does is suggest that the love of a caregiver or family member can “bring them back”, suggesting that their return to lucidity is an ideal state that simply requires a sufficient amount or type of love. *The Notebook* is an excellent example of this phenomenon in that the lucid moments of Allie Calhoun's (Gena Rowlands) experience of AD are directly connected to Duke's (James Garner) recounting of the love story between Noah and Allie.

Thinking upon Harvey's prose and unreliable narrator in *The Wilderness*, there is an undeniable power in more abstract and entropic forms of representation in that they place the reader/viewer in a space that forces them to confront what it means to exist in uncertain affective and cognitive anchoring. And yet, there remains the mooring of the lucidity of prose, as well as the certainty that the book or the movie is just that: something from which we can recede. These practices beg for us to proceed through a guided and curated tour marked by the dramatic undercurrents of a narrativity made necessary by our own desires to “lose ourselves” in the story, or in the even more fundamental need for entertainment.

How can we toss these anchor points aside to be in the moment or to, as Block suggests (Block 2014), “stop looking for the lost person” in our encounter with AD?

Perhaps one way forward is to separate the artistic practice of *representing* AD from the desperate need to recognize a potentiality for the experiences surrounding AD itself. As a result, representational strategies to communicate the experience of AD, even tangentially, seem critically important. More to the point, interactive media seem a particularly powerful mode of conveyance for these experiences in that they more readily incorporate user agency. This analysis is interested in viewing AD as an experience, wrapped in a kind of beautiful sublime. This is not to idealize or to iron over the complexities, and variability, of the lived actualities of those with AD. Even further, this author is acutely aware that, as Zimmerman points out, “illness narratives can never be representative of the population of individuals afflicted by a specific condition” (Zimmerman 2017), to attempt such a thing essentializes the experience of a dynamic and variably progressing illness—particularly in the case of AD.

In truth, as Kitwood and Bredin (1992) point out, dementia does not progress in a uniform or linear way. As a result, what is needed is an approach that offers us some idea of how our senses may not only be unreliable but can undercut our ability to cognitively approach reality, while still considering the variability of individual experience. To this end, one potential avenue has been the burgeoning area of serious game approaches to dementia and AD. While there is certainly a wide range of definitions for serious games (Susi et al. 2007, p. 3), what largely differentiates them from other games is that they are designed for “educational purpose and are not intended to be played primarily for amusement” (Abt 1987, p. 9), but they also allow for different adaptive responses by their users (there is no one way that players/users experience an immersive text). Over the last few years, medical researchers and game designers have partnered to use serious games to explore their health benefits (Wattanasoontorn et al. 2013), better understand AD, and even collect data to early diagnose the disease (Polzer and Gewald 2017, p. 451), but there remains a gap in our understanding of the experience of AD that serious games could fill.

Always is a project that represents an intervention into this space in that it attempts to express the affective and neurological experience of AD. To do this, the project seeks to engage with three major design considerations in relation to AD: approaching social stigma, representation and navigability.

2. Contemporary Stigma around Dementia and Alzheimer’s Disease

While AD, as a diagnosable disease, is now more than a century old, our thinking around treatment and patient care has only recently begun to change. Though AD is well known in the public lexicon, the research of Alois Alzheimer, which provided the backbone for many of the attempts to cure the disease that bears his name, first emerged somewhat unremarkably. Published without illustrations as a summary of research presented at the Southwest German Psychiatrists meeting in 1906, Alzheimer recounted his experience working with a 51-year-old patient suffering from “an unusual disease of the cerebral cortex” (Zilka and Novak 2006, p. 344). Though Alzheimer passed away in 1915 at the age of 51 from rheumatic endocarditis, a great deal of the thinking on this novel disease was the result of these initial steps. In the more than a century that has followed, researchers and medical professionals have come to identify several of the characteristics of the disease, differentiating it from a range of other forms of dementia. As Castellani, Rolston and Smith (Castellani et al. 2010, p. 486) point out, AD begins first with “transentorhinal” disease (attacking areas of the brain across the entorhinal cortex that impact our sense of navigation, our perception of time and memory), followed by “limbic” disease (which impacts our motivation and emotion)—as the first two pathological stages—and finally the “isocortical” stage (impacting higher brain function) in advanced phases of the disease.

More than impacting brain function, AD goes so far as to impact the weight and volume of the brain, much of which appears to be due to “the shrinkage and loss of neuronal processes” (Huang and Mucke 2012, p. 1204). The implications of this physiological change

extend beyond a simple loss of function. Instead of simply eliminating or silencing neural networks, AD “causes aberrant network activity that might actively interfere with the intricate processes underlying learning, memory and other cognitive functions” (Huang and Mucke 2012, p. 1204).

The multi-cognitive impacts of dementia and AD also include a considerable impact on visual acuity. Existing research has shown not only reduced visual memory in AD patients (Vecera and Rizzo 2004, p. 265), but AD also impacts “color discrimination, stereoacuity and contrast sensitivity” (Rocco 2004, p. 139). In addition to the neurocognitive impacts of AD on short-term memory, there can also be considerable impacts on a person’s ability to navigate space due to the physical impact of the disease. Given the early rapid loss of tissue in the hippocampus for those with AD, there is a clear connection between difficulty with navigation and the disease. The way that we visually perceive space is reliant upon location and self-movement cues that orient us through the relation of landmarks to our own cognitive map, but hippocampal damage can disrupt this system by impairing landmark memory (Duffy et al. 2004, p. 153).

Patient-centered care, as articulated via Kitwood (1998), recognizes the complex interplay between this neurological impairment and psycho-social factors (such as health, environment and social context), and is now a central component of dementia and AD care (Fazio et al. 2018, p. S10). Yet, these environmental factors are often treated as secondary or irrelevant in representations of AD. More often, the environmental conditions of AD are shown as victims of the progression of the disease, rather than as directly contributing factors. *Always* functions as an experimental interactive piece meant to explore not only our innate fears of memory loss but also the kinds of stigmatization that still inform cultural awareness of AD. The great contribution of Kitwood (1997) to this discussion is in recognizing the centrality of “personhood” as a key anchoring point for the treatment and understanding of those with AD, characterized as a need for comfort, attachment to place and people, inclusion in their social environment, occupational engagement and the maintenance of their identity. It is precisely these elements that *Always* seeks to explore.

If we are to theorize a representational practice around the experience of AD, then it is necessarily important that we, as researchers and practitioners, consider existent creative practice in relation to the conditions of the disease. Though more experimental industrial practices in narrative filmmaking and literature have sought to capture the “effect” of AD, they often emphasize a heavily curated and controlled expression of the disease. Digital interactive platforms seem a much more effective option given the flexibility and agency that they can yield to their users/players. As Gonzalo Frasca aptly points out, ludological systems operate in ways that differ a great deal from traditional forms of film and literature because rather than operating as a “sequence of signs” that generate their meaning, video games are “sign-generators” that respond and change in relation to user/player decisions (Frasca 2013). To this end, numerous applications have been designed to support physicians in diagnosis (including PEPID and Diagnosis Pro), allow users to check for symptoms of AD themselves (such as ACEmobile), and even support apps meant to help those with AD (Lumosity Mobile, KiMentia, etc.) (Polzer and Gewald 2017, p. 451).

Video games have even been designed to diagnose AD early by collecting data around memory, navigation and other brain health assessments. For example, *Sea Hero Quest* (Sea Hero Quest 2016) is a smartphone app, funded by Deutsche Telekom and made by the game company Glitchers, in partnership with Alzheimer’s Research UK, University College London and the University of East Anglia. The app asks users to pilot a small ship while hunting for sea monsters, and researchers then take the routing data to help investigate memory loss. Similar projects assess brain function, but their focus is on diagnostics and data collection via gameplay, rather than representation or raising awareness (though *Sea Hero Quest*, *Neuroracer* and *Acuity Games: Brain Health* do bring attention to brain health). *Always* is different because it engages with user experience to bring awareness of AD, but also to reduce stigma through empathetic response.

To achieve this, the project deploys and interrogates several key ludological concepts but heavily emphasizes user engagement and flow. Using Gordon Calleja's (2007) engagement model, which analyzes immersion across six distinct frames (tactical, performative, affected, shared, narrative and spatial), the experience of *Always* is mindful of the interrelationship between game space and non-virtual environments. It was critically important that there be a space for users to disconnect from the virtual experience not to be overcome by the frustration of sensorial destabilization as well as the barrenness of its environment. That was one reason that this project was not immediately designed for virtual reality platforms. Unlike *Sea Hero Quest*, *Neuroracer* and *Acuity Games: Brain Health*, which heavily emphasize a comfortable form of engagement that emphasizes the ease of the in-game experience, *Always* creates a tension between the ease of controlling the user character through space and the increasing complexity of navigation—to the point of breaking immersion. This distinction is also similar in terms of game flow, using Csikszentmihalyi's (1990) terminology. It was critical in *Always* that design create a balance between drawing players into the "Zen state" of the gamic experience, while also destabilizing this state to draw user attention to their own frustrations around navigation and memory.

A major part of this destabilization is based on the narrative of *Always*. In wooden and often uneven tones, the narrator of *Always* begins their story by pulling a thread that connects the fantastical with the banal, fairytale ("Once upon a time...") with the everyday ("I found myself wandering..."). Players navigate a large canyon-scape populated with groves of trees that are themselves ensconced in a deep layer of snow. A thick fog extends into the distance and cascading snowflakes relentlessly batter the player's vision. Though the voiceover is audible throughout (with a smattering of related sound cues), the atmospheric howl of the wind and the crunch of players' footsteps in the snow are soon joined by an array of locationally triggered audio tracks based upon the song "Always" (written by Irving Berlin in 1925) that attenuate and overlap themselves across the space. The voice-over tends to layer a range of contextual meanings on top of one another, ranging from the cultural (an adaptation of the life and poetry of Farīd Ud-dīn 'Attār), historical (Irving Berlin's gifting of the song as a wedding present), to the political (Abraham Lincoln's speech before the Wisconsin State Fair in 1859), among others. The core of this narrative layering is the repetition and use of the phrase "this, too, shall pass", which emerges from these layers as a kind of mantra whose usage dances between hopefulness and ironic despair. The cues tell the story of a character searching a library, only to find the poems of Farīd Ud-dīn 'Attār focused on the traveler who learns that all things change (which the narrator relates to their own mother, who often said "this, too, shall pass"). Alternating between the library and the poetry, the narrator soon connects the saying to the phrase's usage throughout history and the impermanence of love and memory. The cues only play in specific spaces on the map, so in such a way, no auditory exploration of the map is the same. The layering of the narrative, poetry and historical references has the effect of melting them all together in the user's mind in that there are too many details to pull together to create more than an ambiguous meaning. As such, the details are unimportant because they are built upon shifting sands that will change when the next sound cue plays. The effect of this experience is that it makes the player yearn for resolution, while the relationships between ideas become more and more complex.

Rather than a fractured and progressively disjunct narrative (often the hallmark of representations of AD in popular culture), *Always* constructs itself in a completely continuous fashion. There are no jump cuts or frantic action sequences; instead, users traverse the landscape at their own pace and without a singular goal identified. Instead, progression through the map rewards them with additional pieces of the story. As Kitwood notes in the epigraph, identity is invariably tethered to a sense of personal and historical continuity. Thus, rather than relying on disjunct forms of confusion (the hallmark of AD representation), *Always* reinforces a sense of temporal contiguity that serves as a backbone for the experience. Though each piece appears only connected by its use of the phrase ("this, too, shall pass"), their juxtaposition reinforces the sense of impermanence that obfuscates

the users' desire for resolution. This is critical because it creates a sense of frustration that underlies the sensorial destabilization that the ludic elements of the game reinforce.

Importantly, the muted landscape strikes a strong contrast to the narration, but it all serves a rather strange affective tone. The sensations of "unbeing" (Kitwood 2012, p. 90) that permeate the piece communicate both the physiological impact of AD, but also the fears surrounding potential memory loss. At the core of this exploration is the quest to engage with our misinterpretation of AD as a "loss of self". Instead, the piece seeks to echo Block's simple question: "If 'we are not ourselves' in the depths of Alzheimer's, who are we?" (Block 2014).

As a design concern, this question is fundamentally important to a representational approach or analysis of AD, as it is precisely this issue that *Always* seeks to explore. In this case, *Always* constructs a virtual reality that, in Loewen's (Loewen 2011) terms, operates as a pool within which we can reflect and project our own identity. The experience of *Always* builds up user reliance on the tools of cognition, but then slowly strips away their reliability. For example, the flashlight that is quite useful early in the game for indicating changes in the canyon's topography eventually is nearly blinding for the player later in the level since it bounces off of the thick fog. Players then have to learn how to rethink how they use visual cues to move through the space (i.e., do they look down more, do they explore the controller to see if there's a button that will turn off the flashlight, etc.). As a result, its structure undercuts not only the very anchor points that we tether ourselves to in perceiving our reality (spatiality and temporality in particular), but it also promotes the very kinds of adaptability that characterize the experience of AD. The purpose of this is two-fold: to explore a kind of beauty in the form of confusion, disorientation and auditory navigation, but also to promote a kind of empathic response through user adaptation to the environment.

Much of the thinking in this design mirrors Kitwood's push to recognize the dignity of AD patients with the idea that "the person comes first" (Kitwood 2012, p. 90). This push, in the mid-1990s, forced a rethinking of many of the ways that care professionals have approached AD patients. Yet, in some ways, the stigma surrounding dementia and AD persists in many of the very representational practices that seek to bring awareness and understanding of them. Cinema has deployed stigmatizing and misleading representations of dementia and AD (Gerritsen et al. 2014, p. 276).

Unlike the mass-mediated representational practices that inform cultural understanding of dementia and AD, their interpretation remains variegated and negotiated. As a result, there is a great deal of variability in the ways that different areas of the world perceive dementia and AD, including "as a normal part of ageing, mental illness, something metaphysical linked to supernatural or spiritual beliefs or as an irreversible disease of the brain" (Batsch and Mittleman 2012, p. 2). Many of those with AD live in fear of acknowledging their own symptoms and remain untreated. Existent research indicates that in wealthy countries, roughly 61% of actual dementia cases remain undocumented in case records, and this number skyrockets to almost 90% in low- and middle-income countries (Prince et al. 2011, p. 10). If we take into account the fact that, due to increasing life expectancy, there were 7.7 million new cases of dementia as of 2010 (roughly one every four seconds)—a number that is increasing on a yearly basis (World Health Organization 2012, p. 2), the increased prevalence of the disease compounds our misunderstandings of it.

Even in those cases where AD is diagnosed, existing stigma can impact treatment. There remain many parts of the world in which those with dementia are "locked away from society, whether in institutions or hidden by family members" (Batsch and Mittleman 2012, p. 7). Such regional variability is also evident in the general social stigmatization of dementia and AD, with those in urban environments often more susceptible to "stigma and internalized shame" around AD than those living in rural communities (Herrmann et al. 2018, p. 323). We tend to view the stigmatization of mental health as a function of a lack of education and awareness, which is somewhat corroborated by research that has shown that those with less education were 2.32 times more likely to stigmatize someone with AD (Blay

and Peluso 2010, p. 163). And yet, research has also shown that mental health professionals often share similar attitudes toward mental health as the general public, even in the face of their additional training (Lauber et al. 2004, p. 423).

For instance, for those in the early stages of AD, a common complaint is “that doctors talk to family members rather than to them, even when they are present” (Harvard Health Letter 2006). This leaves us in the somewhat uncomfortable position of recognizing that, at a time when improved life expectancy is increasing the total number of those with dementia and AD, we have not effectively combatted its stigmatization. Raising critical awareness among medical professionals has been a central concern for a range of professional organizations (including the Alzheimer’s Foundation of America and Alzheimer Disease International), but it represents only one approach to systemic de-stigmatization.

Though lay people who have personal experience with someone with dementia may be “less likely to have stigmatizing attitudes” (Herrmann et al. 2018, p. 322), that hardly captures the very real complexities of the social dynamic surrounding AD. The emotions of family vary a great deal, even within a given cultural context, and this is even more prevalent in the context of the genetic potentialities of AD. Aside from being older, “family history is the second greatest risk factor for Alzheimer’s disease (AD)” (Tanzi 2012, p. 1), so for those family members caring for a loved one who has shared genetics and dementia or AD, it can feel like looking into a mirror at one’s future self. The response to such a circumstance can yield greater acceptance and understanding of how AD may impact our lives, but it can also catalyze fear and further stigmatization (particularly in contexts where family members choose to distance themselves from the patient). Beginning in the 1980s, geneticists have worked to identify genes associated with both early-onset and late-onset AD. Though early-onset AD is “characterized by classic Mendelian inheritance”, late-onset AD is much more difficult to pin down (as it is determined by “genetic risk factors [that] work together with environmental factors and life exposure events”) (Tanzi 2012, p. 4).

Even in contexts where caretakers and medical professionals have diagnosed and begun a care regimen, the potential marginalization and stigmatization of those with AD can occur. AD patients who are non-verbal often perceive that visitors and caretakers “talk around” them, not including them in conversations, and they come to “resent the fact that they are being treated as if they didn’t exist” (Harvard Health Letter 2006). For those in the early stages of AD, there is an unavoidable perception of “difference” in the way that their loved ones treat them. Often, family members change how they interact with those with AD, looking at them differently or even “checking out” entirely (CDC 2015, p. 2).

Even in the context of the family dynamic, complex sociocultural and health literacy factors tend to impact stigma (particularly around the “sub-themes of shame and fear of judgement”) (Herrmann et al. 2018, p. 323). Though stigmatization persists among groups that live in close proximity to AD, such as caregivers and family members, if we are to address larger manifestations of cultural stigmatization of dementia and AD, we need to tackle the critical gap represented by those who are, themselves, quite socially distant from them. This is the core reason that we must reassess the representational practices of dementia and AD, since these serve as key touchstones for cultural awareness of their impacts. It is critical that we not only more fully embrace alternate modes of expression to offer deeper insights into the disease, but also diversify such depictions to model the range of modes by which AD is experienced.

Always represents an attempt to do just that. Utilizing an interactive digital platform (the Unreal gaming engine) alongside experimental media practice, this project functions as a counterpoint to the kinds of mass-media representation of AD that permeate contemporary culture. In place of seeing AD as confusion, punctuated with moments of lucidity, this project amplifies the simultaneous feelings of stability/instability that permeate AD. There is a clear narrative through lines throughout the piece, but the introduction of layers of context necessitates the user/player to focus on aspects of the story, which tend to muddle it. It does utilize a sense of concrete (if only virtual) physical space as its model, but as users navigate the space, the rules of physics seem to subtly bend. The snowfall and

blowing wind serve a double purpose of framing the eerie atmosphere of the scene, but also distracting the user/player and making navigation at certain points far more difficult.

Additionally, the very implementation of the phrase “this, too, shall pass” recalls the numerous elements of language that we use and misuse simultaneously. Commonly misused words like “factoid” (a falsehood) or “ironic” (the opposite of what you would expect) are more than simple misunderstandings of language; they are artifacts of the very living nature of communication. Though often used to suggest that bad times will soon be gone, “this, too, shall pass” carries with it a dual meaning that speaks to the impermanence of existence. The dual meaning of the phrase (as interchangeably hopeful and cautious) draws a line between the words’ meaning and their history/intentionality. This, then, both underscores and undercuts Kitwood’s linking of continuity and narrative with identity. If we frame our reality through sensorial perception, this implies the stability of these inputs. Like a balloon floating just outside our grasp, we reach out in vain to catch their meaning only to be rebuffed by new information or contexts. What remains is a complex feeling rooted in our own engagement with the confusion and visual interplay of the scene around us. This is a great advantage of *Always*, in that each experience of it is different and is dependent on the decisions of the user/player.

3. Situating *Always*: Ethics and Navigable Memory

To better understand how *Always* approaches issues of spatial navigation, memory and audio design, it seems important to begin by looking at one of its major influences: the GPS-driven art piece *Drift* (Rueb 2004). Teri Rueb’s *Drift*, a geolocative audio project, uses GPS and other tracking technologies and invites users “to wander among layered currents of sand, sea and interactive sounds that drift with the tides, and with the shifting of satellites as they rise and set” (Rueb 2004). Set in a 2 km × 2 km patch of sand along the Watten Sea, the program uses GPS data to track the user’s location along the beach and play different audio tracks through headphones, including the sounds of footsteps and excerpts from Kerouac, Joyce and Woolf; audio tracks change based upon user position and the tide. For decades, sound artists (and increasingly augmented reality specialists) have placed their work within physical locales as a means of exploring the potential impacts of spatiality on art (and vice versa). Though a key example of geolocative audio practice, *Drift* is also a critical case study in thinking about the potentialities for “wandering” as a core principle in navigating space—as users have agency in their experience based on when and where they are (though the implications of their choices may not be clear).

Always takes on a similar approach in so far as user navigation directly correlates to changes in sound design (though such a correlation may not be clear to the user). Following the title screen, *Always* users find themselves standing in a small grove of trees, wrapped in a bank of fog with snowflakes fluttering to the ground around them (see Figure 1). In the distance, a faint piano can be heard plodding along through a melancholic melody. There are no directions to indicate to the user where to go, or what to do. Instead, using standard joystick controls (with the left joystick moving the character forward, back and side to side, and the right joystick tilting their view up or down) they navigate the space. Aside from its function as a gateway for exploring representational practices of AD and opening a potential dialogue about the disease (both of which direct their focus toward the development of empathic destigmatization), *Always* also utilizes game design and navigable space, in Wolf’s (2010) terms, to construct a kind of “navigable memory”.

Though the spatial design of the project is quite simple—*Always* is largely constructed as a single long canyon that the user explores in a linear fashion—the falling snow and ascending snow drift tend to make each space seem almost identical (particularly as they become less intelligible and more abstract), leaving the user in the midst of a semi-disoriented state throughout large chunks of the experience. Importantly, this is only an effect since each part of the space is unique in design. As a result, making similar decisions in moments of disorientation will not yield similar results. In place of more goal-oriented ludic experiences (i.e., collecting objects, failure mechanisms, etc.), *Always*

motivates progression through a perceived change in the soundscape and the introduction of audio narrative experiences.



Figure 1. The small grove of trees the player finds themselves in at the beginning of *Always*.

Walking through the snowscape triggers spatially tethered sound cues that serve as the core motivation for user exploration since each cue continues the story. What tools the user is given (like breadcrumbs to mark their way through the forest) are minimalist, though critically important. First, their travels through the snowscape leave behind a trail in the snow that lets them know if they have circled back on themselves (see Figure 2). Yet, as with all the navigable tools, the snow trails tend to help the user as much as they have the potential to mislead them. Playtesting showed that coming upon the snow trail left behind by the player tended to force a choice (rather than reorient users). In which direction do you follow the trail, and how do you know where you might have gone astray? Knowing that you are going in circles does not, in fact, help you to stop going in circles. Instead, it pushes you toward either returning to the same incorrect path you were on before (thus completing the circuit again) or to head back in the direction you came from.



Figure 2. Looking down at the ground the player can see the trail they've left in the snow.

The second tool offered to users is the flashlight they carry with them that glances off the objects in the direction they are facing (see Figure 3). The narrow shaft of textured light is helpful in some of the snowier sections to let users know if they are up against a wall. At the same time, however, the flashlight tends to make you rely upon it too much, and there are sections where it is quite difficult to ascertain, even with the flashlight's help, whether you are up against an object (particularly as the slight inclines of hills begin to mimic the incline of walls as users progress through the map). In such moments, users who have adapted to navigating the space without the flashlight (easily turned off with the click of a button), have a potential advantage in that they are better able to identify the subtle changes in movement that occur when the avatar is walking into a hillside.



Figure 3. The flashlight reflects subtly off of the fog and the hillside.

The third tool is the aforementioned audio cues spread throughout the map. Although they are key to user progression, since their continued playing indicates that the user is proceeding through the map (they are, in fact, unavoidable if the user continues through the space to its “end”), their disconnected narrative often gives the sense that the user has missed part of the story. Alternatively, perhaps, the user is listening to a narrative out of order? As a result, there can be a tendency for users to try to return to areas they have already visited to try to find the missing parts of the story. Once heard, however, the sound cues that have been heard disappear from the map.

These three tools, which are critical for user navigation and understanding of space at the beginning of the experience (since there are no directions, tips, or maps for users to get a hang of the control scheme or navigation), become less useful and more of a hindrance as the experience continues. As a result, though the map is navigable in well less than 19 minutes, on the first playthrough, the experience can last a great deal more as users come to grips with the navigable complexities and second-guess their choices, and they may find themselves running in circles.

In *Always*, what first appears to be a somewhat static and straightforward experience slowly veers off the rails until even the rules of physics begin to bend somewhat (evidenced by trees jutting out sideways from the canyon walls). This does, however, raise a potentially important ethical question in the way that *Always* leads and undercuts its user. The tools also address Kitwood’s (1997) psychological needs in that users find themselves in a desolate and uninviting space (comfort), the increasing abstraction of the environment makes it harder and harder to anchor oneself in such an unusual space (attachment), the user is completely alone aside from a disembodied voice (inclusion), and it feels unclear what they are supposed to be doing, or if they are even working toward a goal (occupation). Yet,

this also raises an important question: does the deployment of these tools mislead the user into overreliance on them, and thus rather than documenting or experientially exploring AD, does *Always* veer into surrealist abstraction—rather than catalyzing affective response?

Oblique abstraction is not the intent of *Always*, and yet it does not clearly articulate its purpose within the framework of the text. It does cling to tropes of documentation in the ways that it deploys history and memory and elements of its visio-audio mise-en-scène. As a result, the ethical “baggage” it carries with it necessitates an analysis that considers both its intent and interpretation. The narrative nature of its unfolding does not tend to make it “feel” like a documentary, and yet it does suppose certain “truths” or “facts” about perceptual reality, which it takes great pains in folding in on themselves. For instance, the use of Irving Berlin’s song “Always” permeates the entire piece as a ubiquitous leitmotif, but its meaning is largely ahistorical and incidental until around the halfway point of the experience when the voiceover contextualizes it as a wedding gift for Berlin’s wife Ellin Mackay in 1925. This additional framing only serves to open a range of additional interpretations rather than crystallize its meaning in the piece.

Perhaps the most important example of the folding and unfolding documentation technique is how *Always* approaches the life and work of the poet Farīd Ud-dīn ‘Attār. Though there has been a range of contexts and arrangements in which the phrase “This, too, shall pass” appears in the historical record (a point that *Always* emphasizes), it originated as a Persian adage made famous, in part, by the Sufi poet Farīd Ud-dīn. Rather than simply incorporating the original poem, or outlining the biography of the poet, *Always* instead adapts the life of Farīd Ud-dīn into an interpretation of his original poem. Though the original poem does not cast Farīd Ud-dīn as its protagonist, *Always* incorporates his actual travels (which were quite extensive) into the story and even uses the details of his actual kidnapping and execution, relating them to the poem’s adaptation in Mojdeh Bayat and Mohammad Ali Jamnia’s *Tales from the Land of the Sufis* (Attar 2001), Edward FitzGerald’s poem “Solomon’s Seal” (FitzGerald 1852), and an excerpt from a 1911 version of the *Encyclopedia Britannica* discussing the poet’s life (Farīd Ud-Dīn ‘Attār 1911). As a result, fact and fiction become entangled and inform one another.

The invocation of this folding narrativity, in tandem with the undercutting of user perception, gestures toward a design that catalyzes empathy through sensorial adaptation. As pointed out by Thomas and McDonagh (2013), human-centered design requires approaches that force designers outside of their empathic “comfort zones” and incorporate the user’s functional needs and wants. In such a way, play-testing for this project incorporated feedback from both users who do not have AD, but also those who do. Such feedback (particularly the latter) was critical in fashioning an experience that could create a sense of discontinuity, without creating a sense of confusion that would drive users away from the experience. Importantly, testers all shared a desire to complete the experience, even if they felt lost or “untethered”. The environment and sound design of *Always* is calming to offset the frustration caused by the unreliability of user senses. As a result, users are able to have the feeling of instability without the disjunct or abstract time-space that AD is often portrayed to inhabit. In fact, the experience is continuous, not disjunct. Thus, it is not chronological but narrative ellipses that drive user experience.

As a result, rather than draw a parallel to a pseudo-documentary, perhaps poeticism and geolocate arts (such as Rueb’s *Drift*) offer a better comparison. Another key example of the spatially oriented approach to media is Janet Cardiff and George Bures Miller’s *Alter Banhoff Video Walk* (Cardiff and Miller 2012), which brings to life, through performance, video/sound editing and cultural memory, the train station in Kassel, Germany, as a place embodied with a range of histories. In this case, participants use their mobile phones and headphones to follow the directions of a muted voice that directs them through the old train station. Throughout the journey, the voiceover runs alongside poeticisms surrounding memory, history (particularly the role of the train station during World War II), and the unreliability of narrativity (as specific moments of the piece subvert user expectations).

4. Conclusions

There remains a great deal of work to be done in exploring representational practices around AD and the promotion of empathic adaptation, but the case study of *Always* opens a range of potential opportunities for exploration. Returning to Block's suggestion that we "stop looking for the lost person" in our encounter with AD, it is not enough to simply rethink our empathic approach to AD and dementia. Instead, it is necessary to promote an awareness of these conditions that centers on self-reflection. As such, this research explored the range of existent representational practices around AD, particularly identifying the tropes of the disease as a fracturing experience. This tends to heavily stigmatize those living with AD as "separate" or "alone", a point that tends to isolate them even further. The result is a massive gap between our understanding of the experience of AD and the everyday lives of those who are adapting and mitigating its symptoms daily.

Always approaches this gap by systematically representing the impacts of AD on spatial awareness, memory and even our visual capacities (through a reliance on a muted twilight color palette). It would be incorrect to think that this piece is a complete representation of the experience of AD, but it is instead an opening into exploring how user adaptation can convey a general sense of the affective and psychological discordance of a kind of AD. As a result, it seems that there is a wealth of opportunities for designers and researchers to think about how empathic design could be used to develop new kinds of experiences that, in Thomas and McDonagh's (2013) terms, expand the empathic horizon of both users and designers. From a design perspective, it is critical not to be focused on essentializing or defining the subjects or experiences of empathic design, as to do so is a disservice to the potentialities of such work. Instead, such work offers opportunities to open up to new ways of thinking about human experience.

The significance of this approach lies not only in the very real need to promote awareness around the implications and treatment for dementia and AD, but it should also signal the potentiality of virtual approaches in representing experience as a gateway to empathy. Ideally, a project like *Always* should spur further research into the role of user adaptation in promoting empathic response. More to the point, it should outline the range of human experience that lies outside of what we come to think of as normalized social existence (whether that is neurotypicality, ableism, etc.).

Though *Always* operates within a virtually constructed space, it functions in a similar way to the Cardiff and Miller piece by offering a range of lenses through which to interpret history, memory and the unreliability with which both history and memory are communicated and interpreted. Much like *Drift*, *Always* invites its user to explore and move around on their own as a process of meaning making, but inherent to this act are the imbrications of limited perception and navigability. Rather than forcing a singular interpretation through its structure and interface, users base their experience on a range of factors including, most importantly, how much contextual information they have received regarding designer intentionality. Though users who experienced the work without any context similarly tended to latch onto a similar affective tone in the piece, unsurprisingly, the contextualization of *Always* in relation to AD tends to create a more powerful and directed emotional response. While this does not entirely limit interpretations (different users may identify with particular elements of the piece based on their own referent systems), it is far more effective in developing systems of empathic engagement. The context of AD tends to channel attention to those aspects of the work that play with memory, moving beyond an artistic exercise into one concerned with navigation, cognition and extra-aesthetic meaning making.

And yet there remains, just out of our grasp, a unified meaning or truth that could draw all these contexts together. Ultimately, we are left with little to hold onto beyond the meaning we can construct in the moment, but, as the narrator points out, at the end of *Always*, these interpretations mean nothing (or, perhaps, everything) because "what do I know. I'm not even here" (*Always* 2021). Yet, if we are not here, then who is?

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