

Article

Anamnesis: Intertextual Memory and Alzheimer's Disease

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Abstract: This essay develops and performs a theory of intertextual memory; and uses this concept as a heuristic to re-conceptualize identity for people suffering from Alzheimer's disease. This work emerges from three key sites of personal and cultural inquiry. At the center is my engagement with my matrilineal ancestry; which is haunted by the specter of memory loss: my mother's mother (my Nanny) was diagnosed with Alzheimer's disease (AD) in 2002 when she was 73; and my mother was diagnosed with Early Onset Alzheimer's in 2012 when she was 51. By telling stories about my mother and my Nanny which rely on intertextual memory; I hope to broaden the poetic space of remembering and to challenge the Western humanistic conception of identity as inherent; atomistic; and highly dependent on successful memory performance. Secondly; I examine the rhetorical discourse circulating Alzheimer's disease in the popular cultural imaginary; where illness metaphors deleteriously situate the forgetting body within narratives of failure; fear; and loss of personhood. I argue that an intertextual approach to memory performance can help us reimagine Alzheimer's patients outside the stigmatizing parameters of these broader cultural stories. Lastly; I draw on empirical research related to communication failure in AD in order to consider the ways caregivers might approach Alzheimer's patients with the kind of linguistic and interactional flexibility subtended by an intertextual approach to identity; in order to forge improved relationships both with Alzheimer's patients and with the disease itself.

Keywords: memory; matrilineage; narrative inheritance; Alzheimer's disease; intertextuality

1. Foundations

My matrilineage is one of forgetting. This is both metaphorical and biomedical: My mother's mother (my Nanny) was diagnosed with Alzheimer's disease (AD) in 2002 when she was 73. My mother was diagnosed with Early Onset Alzheimer's in 2012 when she was 51. My Nanny's diagnosis came mere weeks after my granddad's sudden death by aortic dissection. There is perhaps no catalyst like grief for cognitive impairment. My mother and her siblings realized almost immediately that my granddad had been "covering" my Nanny's discernible early symptoms. A month after the funeral, my mother flew her mother from Halifax, Nova Scotia to our home in the suburbs of Chicago, where she stayed with us for six months of every year for the next seven years until 2009, when my aunts placed my Nanny in a permanent care facility. In 2012, my mother, who had been suffering from noticeably impaired short term memory for over a year, visited a neuroscientist in secret and relayed her diagnosis to a select few, including myself. Her disease has remained an almost entirely unbroached topic per my mother's stalwart desire to continue living her everyday life as unburdened as possible by the psychological and emotional stress that accompanies such a weighty diagnosis. While the advancement of my mother's disease has thankfully been much slower than her neurologist predicted, my Nanny progressed from the early to the late stages of AD within the span of only five years—a staggeringly swift descent.

This is a project about the complexities of (un) forgetting. I seek here to develop and perform a theory of intertextual memory, and to use this concept as a heuristic to re-conceptualize identity for people suffering from Alzheimer's disease. This work emerges from three key sites of personal and cultural inquiry. At the center is my engagement with my matrilineal ancestry, which is haunted by the specter of memory loss. By telling stories about my mother and my Nanny which rely on intertextual memory, I hope to broaden the poetic space of remembering and to challenge the Western humanistic conception of identity as inherent, atomistic, and highly dependent on successful memory performance. Secondly, I examine the rhetorical discourse circulating Alzheimer's disease in the popular cultural imaginary, where illness metaphors deleteriously situate the forgetting body within narratives of failure, fear, and loss of personhood. I argue that an intertextual approach to memory performance can help us reimagine Alzheimer's patients outside the stigmatizing parameters of these broader cultural stories. And lastly, I draw on empirical research related to communication failure in AD in order to consider the ways caregivers might approach Alzheimer's patients with the kind of linguistic and interactional flexibility subtended by an intertextual approach to identity, in order to forge improved relationships both with Alzheimer's patients and with the disease itself.

In order to bring my mother and my Nanny into view, and to demonstrate the intertextuality of familial and personal memory, I would like to tell some stories. Using storytelling as a methodological framework is, to me, not just obvious, but necessary for this work. Every effort to remember requires the narrativizing of experience. Stories are a useful mechanism for bringing into public view individual experiences that, however particular, can be understood as reflective of more collective encounters. Additionally, it would be difficult, and I would argue, less productive, for me to theorize identity performances of Alzheimer's patients in general without attending to the specific histories and movements of the forgetting bodies closest to me. To invite my readers into the intimate dynamics of my family is to perform the adage of the personal as political. I believe that every act of storytelling offers the possibility of glimpsing what's at stake in public culture; and, as we shall see, the stakes for those who are losing their memories are high.

And so we begin.

2. Performing and Theorizing Intertextual Memory

The ocean collects stories; carries a chronology of bodies. Flighted bodies. Swimming bodies. Bodies of land. Bodies that breathe, and that don't. Millions of them, named and unnamed, shedding bits of themselves in swelling seas across millennia. These stories scatter like light waves beneath the surface. Swallowed and submerged in this archive of accrual both infinite and recursive.

Even though I was raised in a landlocked state, the ocean is in my blood. I come from a long line of women who lived on the shores of the Atlantic. My great-great-great-grandmother Virginia was born in 1850 in Bridgeport, England—where cascading cliffs meet the northwestern edge of the English Channel. She married James William Kenway, a prominent local fisherman, and made the journey with him to an English outpost in Placentia Bay, Newfoundland in 1867. Their son, Charles Kenway, born in 1878, died young and never saw his daughter, my great-grandmother Maryanne, leave Newfoundland for Halifax, Nova Scotia at the outbreak of the First World War. Maryanne went to live with her Uncle Jim and find work and opportunity in the "big city". She met and married my great-grandfather Roy Noseworthy at twenty-two, and they moved into the bottom level of a two-story flat on Hollis Street a mere 200 yards from the waterfront. Maryanne had four children, two boys and two girls, including my Nanny, Thelma, their second child, born in 1929. Just three years later, at thirty-two, my great-grandfather succumbed to the tuberculosis he contracted working as a steeplejack—cleaning factory chimneys up and down the banks of Halifax Harbor. Maryanne found work cleaning houses and charged her oldest daughter, Peggy, with caring for her three younger siblings during the day. Peggy tells me that of the three, my Nanny was the most rebellious—daily abandoning household chores to chase seagulls down the port docks. "She was an outdoor girl," my great-aunt Peggy says,

“never could keep her inside. One time, our neighbor, Mrs. Oliver, found Thelma during the middle of the school day, skirt hiked up, knee deep in the water outside Fisher’s Bottling Works collecting sea glass. And she pulled her right on back to the schoolhouse—all seventeen blocks—by the ear.” My Nanny collected sea glass well into her sixties.

When the Second World War came to Halifax, the city bustled with sailors and armament factories. In 1942, my great-grandmother’s landlord sold their flat from under them to the owner of a local glass factory, so she moved her four kids thirty-three miles west of the city into a one-room house at the head of St. Margaret’s Bay. Five years later, my Nanny met and married Ron Dillman, a blacksmith apprentice in the Royal Canadian Navy. They couldn’t afford to return to the city, so my granddad bought a cheap plot of land off his master’s brother down the road from a little brown Anglican church my Nanny loved. And there, a stone’s throw from the eager Atlantic tide, he built a small A-frame house where my mother and her five siblings spent their childhoods breathing in the salty air.

I want to pause here for a moment. Because I’d like to think that this portion of my family’s story is somewhat stable—it’s been collected through compatible personal interviews with family members and “officially” validated by a genealogy study conducted in 2007 by my second cousin. But from here on out, the stories start to get slippery. The details of my Nanny’s adult life and my mother’s childhood come to me through a panoply of photographs, letters, newspaper clippings, and a host of fluid, often contradictory oral narratives delivered by dozens of family members sitting together around campfires or at dinner tables during our yearly family gatherings. All these stories are troubled by alternate tellings. What one insists, another denies. And so the “truth” is often no more than a compendium of patterned details. To see the whole picture, one has to move around. And so I say again

And there, a stone’s throw from the eager Atlantic tide, he built a small A-frame house where my mother and her five siblings spent their childhoods breathing in the salty air.

See—this version of the story sounds idyllic, but that’s the thing about versions. There are always others. And in a different version what you would need to know is that my Nanny and granddad were poor. The kind of poor I’m lucky never to have experienced. I will never know the difficulty my Nanny must have faced as my granddad descended into alcoholism and she was forced to double her house-cleaning load to keep powdered milk and potatoes on the table for her growing family. I only know that my mother describes the mother of her youth as “angry and stressed,” and that there are only a few photographs from these years where my Nanny is smiling. My aunt once told me that by the time my mother was born, my Nanny was tired of raising children.

The story of my mother’s early childhood is one I know well. But by “know well,” I simply mean I have the general facts. Not the details. Not the texture. To tell this story, I have to invent. The telos becomes not truth, but affect. Perhaps some memories can exist only as a feeling. But this remains important—to feel something as true

In 1960, my mother was born into blue. The cerulean of her mother’s eyes—piercing and crystalline. The eyes of a mother turned hard from the sweat of providing for children she was no longer sure she wanted. The birth of my mother—the last of six children—made my Nanny ill. Loss of blood. Infection. She sent my mother from the hospital into the care of a French nurse who lived down the road for the first two months of her life. It was snowing the day my mother finally arrived at her parents’ door in late November. The winter trees could bear birds but not leaves. (What things can a cold heart bear?) At two months, my mother didn’t even have a name. My Nanny greeted the nurse at the door and asked for hers. My mother is the namesake of a different pair of blue eyes. The little white house where my mother grew up had only two bedrooms for eight people. At night, my mother would lay awake for hours. Listen to the music of water reaching for sand. With no lamp burning, the dark room was window-lit. The moon filtered through the fist of geraniums on the sill. A blooming red boundary between inside and ocean. When I visited this room in the summers of my own youth, the child body of my mother was long departed. But time held its breath in those curtains and I could still feel the eager eyes of my mother, stretching into the darkness towards the black midnight waves.

This kind of memory is phantasmagoria—constantly aggregated, challenged, imagined and reimaged—not unlike the sifting, shifting currents of the sea. This is the kind of memory that makes the most sense to me because I understand memory as assemblage—similar to Certeau (1984) description of memory as an “anti-museum” (Certeau 1984, p. 108). (What is the opposite of artifact?) Certeau insists that memory is “that which can be dreamed about a place” (Certeau 1984, p. 108). Dreaming implies invention; invention requires creativity; and creativity is never stable, and often collaborative. To remember in this way moves us away from Western humanist conceptions of inherent, fixed personhood—where identity is validated by one’s personal experiences and the “proper” performance of memory. Expanding the poetic space of remembering to include the shaky somatic repertoires of affect and the possibility of more than one story is at the heart of what I call *intertextual memory*.

It is certainly the case that memory matters to a person’s subjecthood and identity. When Judith Butler (2005) writes about constructing personal stories in *Giving An Account of Oneself*, she tells us how they fail to meet Kantian standards of knowledge. For Butler, writing stories about ourselves is a way to make our subjecthood legible. The difficulty in doing so, however, is that while these stories do point to a “bodily referent,” at the same time “the stories do not capture the body to which they refer” (Butler 2005, p. 38). Instead, the narrative is perpetually “disoriented by what is not mine, or not mine alone” (Butler 2005, p. 37). For Butler, the story of the self is always already imbricated with the stories of others. Our stories, our memories, are never our own, but are rather distributed. Karin Barber (2007) writes something similar when describing non-Western indigenous ideas about personhood. A person, Barber writes, is conceived as “multiple, dispersed, unbounded and split, because he/she is *part of other people, or is made up of other people*” (Barber 2007, p. 104, emphasis added). In this way, we can understand personhood not as given, but as made, as constructed, and importantly—as relational. Alfred Gell (1998) calls this “distributed personhood” and understands identity as best represented by the idea of the “extended mind” whereby “a person and a person’s mind are not confined to particular spatio-temporal coordinates, but consist of a spread of biographical events and memories of events, and a dispersed category of material objects, traces, and leavings, which can be attributed to a person and which, in aggregate, testify to agency . . . The person is thus understood as the sum total of the indexes which testify, in life and subsequently, to the biographical existence of this or that individual” (Gell 1998, pp. 104, 222–23). I argue we could understand not just agency, but also memory this way. A person’s memory, therefore, is “deposited and preserved in traces left in the material world on which he/she has acted,” and further, in the people with whom he/she has interacted (Barber 2007, p. 104). There are cultural gains to be made in recognizing that memories do not exist in a single consciousness, but rather belong to a collective one that can grow, learn, and heal by expanding the repertoire of stories constituting it. As Bakhtin (1986) writes, “the text lives only by coming into contact with another text” (Gell 1998, p. 162). The perpetual aggregation and movement of personal stories makes possible the kind of organic vitalism that keeps memories and bodies alive, and, as I will argue, allows for productive engagement with those who seem to mis-perform memory.

Memory as outlined here, as contingent and relational, I call *intertextual*. “Intertextuality” is a concept introduced by French philosopher and semiotician Julia Kristeva in the sixties—drawn out from the work of the Bakhtin circle some forty years prior. The term is derived from the Latin *intertextus*, meaning “an interweaving.” In “Word, Dialogue, and Novel,” Kristeva (1980) challenges the structuralist idea of the singular authorship of texts and argues that texts are not sealed semiotic systems, but rather constituted by their relationships to other texts and to the structures of language itself: “any text . . . is constructed of a *mosaic of quotations*; any text is the absorption and transformation of another” (Kristeva 1980, p. 66, emphasis added). The metaphor of the mosaic is a useful one for thinking about memory as a text. Anthropologist M.J. Fischer (1994) has conceptualized memory in this way:

Memory is layered in differently structured strata, fragmented and collaged together like mosaics in consciousness and in unconscious maneuverings, all of which takes

hermeneutical skills to hear and unpack, which in another sense might also be called Mosaic, as a figure of the hermeneutical traditions created in the interface between orality (face-to-face, relational, immediately monitored-adjustable communication) and literacy (distanced, ambiguously playing on the graphics of absence) (Fischer 1994, p. 80).

Intertextual memory is thus a combination of material texts, somatic experiences, metacognitive reflection, and relational interactions or orientations (Bauman 2004, p. 4). As Fischer (1994) continues, people “construct their sense of self out of pieces that come from many different cultural environments” (Fischer 1994, p. 80).

If my Nanny could be called radiant, it would be when she sang. She had a deep almost raspy voice. Something like Janis Joplin meets Nina Simone. Her jaw would move forward and back and her eyes would get wide. She’d spin my sisters and me around the kitchen. She’d pull my granddaddy off the couch and they’d dance in clumsy circles while he harmonized with his sweet baritone. She had two favorite songs. “These Boots Are Made for Walkin’” and “Hey Good Lookin’.” We didn’t listen to a lot of country in my house. My father loved the Rolling Stones and Led Zeppelin and Pink Floyd. But I knew Nancy Sinatra and Hank Williams. I remember my Nanny tapping the kitchen hardwood with her ballet slippers as she yelled out “Come on boots! Staaart walkin’!” My Nanny smelling like bacon and old lipstick as she grabbed my hands and twirled me until I was dizzy.

Driving to Halifax, Nova Scotia from Chicago is a two-day affair. The second day is longer. The roads are windy and the speed limits are lower. Typically we arrived at my grandparents’ house around 1 AM. Though their usual bedtime was 9 PM, they waited up. Both of them. Sitting in their respective chairs in the living room—the deck light switched on for us. And every year without fail, a pot of soup was ready on the stove. My sisters and I would ask for a small bowl before we went to bed. My Nanny would refuse. We would sprint upstairs and jump into bed excitedly, beseeching sleep to come faster. There was some sense of victory if you were the first up. The first to run downstairs and ask for soup for breakfast. My Nanny always had the cereal out. Always asked at least twice if we were sure we wanted soup. “Yes!” we squealed. And she would smile. Butter some bread. Serve us soup in little bowls with pink flowers on the bottom. Her kitchen smelling of celery carrots pepper onions turnip potatoes mushrooms chicken. Our throats warm. Our bellies full. My Nanny offering us seconds.

At the end of each summer visit, we brought my Nanny and granddaddy back with us. They slept in the little third floor bedroom. They stayed until after Thanksgiving. My granddaddy sat on the far right cushion of the big living room couch, staring out the bay window at the squirrels. He named them. My Nanny cleaned, cooked, made our household rigid. From August to November, my mother acted strangely. She didn’t cook any meals. She didn’t sit at the head of the table. She became quiet. One Sunday night, my Nanny was in a foul mood. My little brother and his friends had made a mess of the kitchen. I was at the table doing homework when my Nanny walked in. “Outrageous,” she said. “Kirstin, you get up and you clean this mess. Your mother doesn’t need to come home to a pig sty.” I had a project due in the morning. The mess wasn’t mine. My body was learning adolescence. Learning rebellion. I didn’t move. “Kirstin,” my Nanny said again. “You hear me?” I explained about the project. My mother came through the door while I was talking. I looked at her to rescue me. I made my eyes a plea. My Nanny’s voice reiterated slowly: “Kirstin. You. Clean. Up. This. Mess. Right. Now.” Her words in my gut. Her gaze incisive. Blue eyes unblinking. I kept my eyes on my mother. Cocked my head. Made the silence into “please.” My mother’s voice quiet. “Kirstin. Listen to your Nanny.” Her eyes holding something. Something like fear. Something like shame. I cleaned for an hour.

Sometimes grief is pathologic. After my granddaddy died, everything changed. My Nanny couldn’t be in their house alone. She came back to Chicago with us and stayed until after the New Year. It started small, but happened fast. Forgetting which drawer contained the silverware. Forgetting which day it was. Forgetting whether she had eaten lunch. Each year, her condition worsened, and my mother eventually hired a full-time caregiver, Kvetka. The woman entered our home under the

pretense of caring for my younger siblings—making sure they got to all of their summer activities. If my Nanny knew why Kvetka was actually there, she never said, nor questioned my mother. The last time my Nanny came to stay with us, I was twenty and home from college for the summer. My older sister was on a mission trip in Ghana. Kvetka's mother had fallen ill and she had flown back to Romania with little warning. My mother put me in charge.

I woke every day at 6AM. Waited for my Nanny to stir. Picked out clothes for her. Led her to the bathroom. Turned on the shower. Helped her step in. Pressed a green loofah to her wrinkled skin. Hummed Hank Williams. Made a game out of getting dressed. Out of taking pills. Some days she looked at me with appreciation. Some days disdain. Most days confusion. I sat with her on the patio, our dog Cody on her lap, and watched while she re-read the same two romance novels and struggled with the crossword puzzles she used to excel at. I brought her water and monitored her temperature. There were some things she insisted on doing herself. Cooking was one. One afternoon, I came into the kitchen and saw her looking at the sandwich she was making. She turned to me holding the half-buttered bread. "Someone started making this sandwich. Should I finish it? Who is it for?" Her eyes concerned. When my Nanny went back to Halifax that January, my aunts put her in a nursing home. I didn't see her again for two years.

On a Friday afternoon in August, I stand next to my mother on the warm sand of Schooner Cove at the head of St. Margaret's Bay. Our car is parked illegally on the side of the road, 100 yards from the driveway of her childhood home. She has kicked off her black heels and left the driver's door open. The water laps at her ankles. She makes shoes of wet sand in the shallow waves. She looks straight ahead, to where sky touches ocean, and she is both fiercely present, and quickly receding. Her body—terrified and unheroic in a way I've never seen before.

That morning, we had visited my mother's mother at the Sunrise Nursing Home in downtown Halifax. My mother was supposed to go with my Aunt Sherry, but Sherry lost her nerve. So my mother asked me to come. My siblings and cousins were going to the beach. We had a picnic packed. I was wearing my swimsuit. I wanted to lie in the sun and get brown and take pictures to post on Facebook. But something in my mother's voice was urgent. We drove with the radio on. We sang along to Sarah McLachlan. The sign for Sunrise was purple, with a cartoon sun giving a thumbs up. Inside, it was like a hospital. Sterile. Fluorescent. Everything smelling of disinfectant. We walked to room 14D. Found my Nanny sitting on the edge of her bed in the dark. Nobody had opened her blinds. It was 11AM. I watched my mother approach the crumpled woman. Take her hands. My Nanny looking into the face of her youngest daughter. Her expression unchanging. My mother looking into the eyes of the woman who raised her. The woman who had bred fear in her. My mother's soft cheeks a little sunken.

"Hi, mom," she said.

"Oh," my Nanny replied. "Is it lunchtime?"

My mother's eyes searching. Her voice steady.

"It's me, Annette."

My Nanny's eyes shifting from my mother's face to me then back to my mother.

"Oh," she said slowly, looking down at the floor.

My mother rubbing my Nanny's hands. My mother breathing slow breaths.

"Would you like to go on a walk, Thelma?" my mother asked, her tone raised.

"Oh, I suppose," my Nanny answered.

We walked with her around the building, to the game room, the cafeteria. Sat for a while in the garden. My mother holding her mother's hand. My Nanny's eyes resting only briefly on everything we passed, as if looking for something. My mother asked her questions she only vaguely understood, and listened as my Nanny spoke to her as she would a stranger—this vacant language undoing the tether of daughterhood to which my mother so desperately clung. It is a strange thing—to grieve a body that is right beside you, but does not know you. When we got back to 14D, my mother told me to go to the car. I hugged my Nanny goodbye. She smelled like antibacterial handwash. And a hint of old lipstick.

I waited alone in the heat for half an hour. When my mother returned, she got in and started the car without saying a word. We drove for a while in silence. I tapped the door handle with my forefinger as we curved along the coast between blue and pine. Finally my mother spoke. "I signed the DNR," she said, both hands tightening around the steering wheel. I put my hand on her arm and watched as she started to speak, then sighed. Then wept. The hot air heavy with salt.

I look behind me through the trees on the far side of the road, and can make out the chipped white paint of my Nanny's house. I can feel the disquietude of my family waiting for us inside. I turn back into the salty headwind and inhale deeply. My mother wades in further, and I follow. Though it has been decades since she left the ocean behind, her feet navigate the shifting sand beneath us with graceful ease. "The beach used to be so much bigger," she says as she glances at the houses to the east. Without looking down, she drops her hand to her side and her fingers grasp at the cresting water in time with its pulse. She looks big and small—as if readjusting to a place she belongs. She turns back towards the shore and scans the tree line. "See that red spruce with the broken branch at the top?" she asks and gestures with dripping hand. I locate it and nod. "I used to climb that all the way to the top." I look at her, disbelieving. "Mom, that tree has got to be fifty feet tall." "I did," my mother assures, her brown eyes locked on the summit. "You can see all the way to Peggy's Cove from up there." The vastness of her claim penetrates deep into my belly and I suddenly feel a bitter longing for this version of my mother, young and fearless, making friction between outstretched hand and rough bark as she ascends. Branches taking her up and away from everything below. As I turn back towards the blue horizon, I catch a glimpse of green hillside and brown steeple. "Is that St. George's?" I ask. My mother doesn't need to look. "Of course," she says. I cup my hands around my mouth and yell into the wind. "Hello, granddaddy!" My mother smiles and stares and I know she's trying to make out the anvil shaped gravestone, but it's too far away. "We should go," my mother says after a while, and turns south once more towards Peggy's Cove. She closes her eyes and seems for a moment to leave her body entirely. Above us, a flock of gulls rides the moving air. They appear to float instead of fly. I close my eyes, too. If you're not used to it, standing with eyes shut in the ocean tide can cause vertigo. The briny breeze, the water advancing and retreating. Your body can't help but shift with it. Your proprioception begins to fail. You think you might fall. I suddenly understand what my mother is doing. This is what forgetting feels like. A rhythmic, oneiric state of being; a reality of incessant descent. Everything in waves. My mother, caught between the arms of her two mothers. One, frail and disappearing. The other, cosmic and melancholy, holding her in a blue embrace. I think of all the stories curling around rocks in these waves. All the mothers and daughters. All the memories. All the coastlines. All the waters we enter, and that enter us. All the floods we release, and hold back.

3. Alzheimer's Discourse and the Dangers of Metaphor

Storytelling is the process through which the polysemic intricacies of bodily experience are translated into comprehensible trajectories through the imposition of a narrative line onto disparate images and movements. As a cultural practice, this process delimits the possibilities for understanding and engaging the individual experiences of certain abject bodies because the dominating grammars write these bodies into recurring generalized narratives with delineated plot points. This has

deleterious corporeal and ontological consequences, since the social construction of these bodies often becomes their social abjection—the making of vulnerability through the dismantling of normative subjecthood. Alzheimer’s disease, like many serious illnesses, becomes comprehensible in our cultural imaginary through reliance on patterned metaphoric tropes. Lakoff and Johnson (1980) have described in detail the ways metaphors make cultural meaning, and Susan Sontag (1978) has explored the rampant use of metaphors to understand disease—often with harmful consequences. Illness metaphors, whether representative or misrepresentative, certainly provide “additional information about the structure, content, and meaning” of the disease, but it is important to pay attention to the ways different metaphors work differently to constrain or enable various understandings of illness (Sackmann 1989, p. 465). For a disease like Alzheimer’s, metaphor use is particularly prolific, because, as Sontag (1978) argues, “any important disease whose causality is murky, and for which treatment is ineffectual, tends to be awash in significance” (Sontag 1978, p. 58). Indeed, poetic, autobiographical, and scientific literatures about AD are rife with metaphoric representations of the disease. What is troublesome about Alzheimer’s discourse is that circulating metaphors tend to reinforce the “stigmatization, shame-attachment, silence, and secrecy” already associated with AD (Johnstone 2013, p. 40). In a thanatophobic society such as ours, there is a tendency for terminal and regressive diseases like AD to become stand-ins for death—and cultural rhetorics substantiate this effect. What results is not only a potent “politics of paranoia” surrounding the disease, but also a circulating metaphorical reification of negative ontologic constructions of the AD sufferer (Sontag 1978, p. 69).

A brief overview of the prevailing tropes surrounding AD will reveal these problematic ontologic effects. In her extensive study of Alzheimer’s Disease, Australian healthcare ethics scholar Megan-Jane Johnstone (2013) draws on a host of wide-ranging data including news media reports and commentaries, documentaries, courts and court reports, films, websites, professional literature and government and non-government agencies, in order to explore public attitudes towards and media representations of AD. She identifies three predominant metaphors: the Epidemic metaphor, the Military metaphor, and the Predatory Thief metaphor. The epidemic metaphor, characterized by terms such as “epidemic,” “plague,” “immune,” “afflicted,” “you can catch it,” “affect everyone,” and “waves rolling,” creates a sense of cultural fear and panic, whereby those suffering remind the healthy of the threat of the disease which can “affect anyone” and which “lurks in plain sight” (Johnstone 2013, p. 35). This metaphor is perhaps best exemplified by PBS’s 2004 broadcast, “The Forgetting: Alzheimer’s—Portrait of an Epidemic.” The broadcast abounded with references to Alzheimer’s as an epidemic:

“This is the disease that **can affect anyone**. There is not a single person on Earth who is immune to Alzheimer’s disease . . . we’re in the middle of an **epidemic**. We absolutely have to stop this disease. There’s just no choice. As a nation, as an economy, as a civilization, we have to end it now” (PBS 2004).

“In Hospitals and clinics across the country, doctors see hundreds of thousands of new patients each year as the **epidemic** of Alzheimer’s continues to grow” (PBS 2004).

“It used to be just this individual tragedy. Now it’s an individual tragedy that is happening so many times it’s becoming a social tragedy and an economic tragedy. Every year past age 65, the percentage of people with Alzheimer’s increases. By the time you reach 75, you have a 10% chance. If you live past 85%, the numbers are much worse. Anywhere from 25% of the people over 85 to even as high in one study as 47% of people over 85 have some level of dementia. That’s an **incredible number of people** with the disease” (PBS 2004).

For Alzheimer’s sufferers, this conception of the disease effaces their idiosyncratic experiences by casting them merely as a singular number amongst a growing diagnosis rate which breeds fear in the aging population.

The Military metaphor relies on terms such as “invades,” “attacks,” “enemy,” “strikes,” “hits,” “explodes,” “fight,” “destroys,” “kills,” and “wins” (Johnstone 2013, p. 36). A sampling of recent headlines reveals the proliferation of this language:

- “Walk to Fight a Silent **Enemy**”
- “Alzheimer’s Disease The **Enemy** Of 85-Year-Old Author”
- “Thousands Walk to Back the **Fight** against Alzheimer’s”
- “Drug Stalls **Attack** of Alzheimer’s”
- “Alzheimer’s and How It Can **Strike** Anyone at Anytime”
- “Alzheimer’s **Strikes** Women Harder than Men”

The use of military metaphors to conceptualize disease in the public imaginary is hardly unique to AD, and has been theorized by a host of cultural scholars and physicians alike. By describing a patient’s approach to his/her disease as a “battle” and the patient and his/her illness as the “combatants” therein, the process of dealing with disease becomes fundamentally adversarial, and the “outcomes” become dichotomized into victory and defeat. Such discourse places a heavy burden on the sufferer, who often feels pressure to be a “fighter,” and who comes to perceive setbacks and treatment plan changes as indications that he/she has not fought hard enough. For those who “lose” their battle, these rhetorical constructions are even more problematic because they position deceased sufferers as failures.

The Predatory Thief Metaphor conceives of AD as a “criminal” who “prowls,” “sneaks,” “creeps about,” “robs,” “steals,” and “deprives” sufferers of their memory, language, and brain function (Johnstone 2013, p. 38). Like military metaphors, criminal metaphors identify the disease as an enemy, but the latter further articulate the sufferer as a “victim.” This construction functions rhetorically not only to create fear, but also to perpetuate the already nascent feelings of helplessness and (self-)pity associated with the disease.

Perhaps the most deleterious metaphor circulating in the public discourse about AD is that of loss of self. Even colloquial definitions of Alzheimer’s tend to characterize it as a process of “losing one’s mind.” Indeed, etymologically, dementia—the medical term for a brain disorder that affects communication and performance of daily activities, of which Alzheimer’s disease is one particular form—is Latin for “a being out of one’s mind.” An oft-cited example of this rhetoric is Washington Post staffer Lawrence Meyer’s 1982 series of articles on Alzheimer’s disease. In the second article of the series, “A Family Stranger: Irreversible Illness Alienates Victim, Afflicts Those Who Care,” Meyer quotes at length from an interview with Dr. Robert Terry, a neurologist. Terry explains what he understands to be the “scariest” aspect of Alzheimer’s disease by arguing that:

although cancer kills you ... it doesn’t **remove your very humanity**, your intellect, your personality, your personal habits of hygiene. It doesn’t turn you into a vegetable. It kills you, fine. We all have to face that. But I don’t want to be **destroyed as a human**. It seems to me that that’s the essence of why people were so ashamed for years of mental illness in general. Having cancer or tuberculosis was not sinful. But mental disease is—was. That’s because it changes our very soul, our very spirit. It **lessens our humanity**. All diseases are depersonalizing to some extent. But you’re still human. You can still respond to pain, anger, to hunger, to whatever and you’re still thinking. But a person with serious dementia is **no longer human**. He’s a vegetable. That’s devastating. Fearsome. Terrifying, to anyone who’s ever seen it—the thought that that could happen to you. (Meyer 1982, p. A10, emphasis added)

Cultural narratives like the one traced here through Robert Terry, which perpetuate the trope of “loss,” are problematic because they create an associative link between the mind and the self, whereby the “loss” of certain cognitive functions—specifically the loss of language and the loss of memory—becomes representative of a loss of identity and personhood. This understanding of AD is complicit with Western humanistic conceptions of an a priori self which exists prior to the symptomatic

expression of the disease and which, in the absence of successful language and memory performance, is consequently effaced by it (Rieske 2012, p. 8). Thus, as one becomes more symptomatic, one becomes “less” of oneself and indeed “less” human. This notion that having advanced dementia makes someone “no longer human” functions discursively to degrade, debase, and wholly erase the AD sufferer. Terry’s use of this trope is arguably harsher than most, but the metaphor of loss of personhood has endured and remains potent in our contemporary public discourse. JUANNE CLARKE (2006) has written about the use of “missing persons” to describe those with Alzheimer’s disease (Clarke 2006, p. 274), while Daniel George and Peter Whitehouse and George (2008) have referred to their “left behind bodies” (Whitehouse and George 2008, p. 23). Sweeting and Gilhooly (1997) have written extensively about dementia as “social death” and argued specifically that “society may view or treat the dementia sufferer as a liminal or non-person, who is demonstrably making the transition from life to death” (Sweeting and Gilhooly 1997, p. 99). In these narratives, the sufferer is first overtaken by AD and then dislocated by it; Alzheimer’s in effect erodes “a person’s core personality and selfhood . . . Though the person is there physically, a discontinuity exists between his identity before and after the onset of the illness” (Hinton and Levkoff 1999, pp. 459, 461). These metaphors found their way into the mouths and minds of my own family members as well.

On a summer evening shortly after my eighteenth birthday, I found my mother sitting alone at the kitchen table. In a family as big as ours, seats at the dinner table are assigned—not by force, but rather by the unspoken agreements that accompany sibling hierarchies and shifting family dynamics. It was just after dark, long after dinner, and my mother was seated not in her usual position, but in the seat her mother had claimed since her arrival in February. My mother’s fingers were carefully thumbing through the *Jumbo Crossword Book: Large-Print Edition* that my Nanny had left on the table. I approached her from behind, following her eyes with mine to the black squares on the page and the blue ink markings from my Nanny’s pen. Handwriting is a thing I love; the way the letters suit the writer. My Nanny’s handwriting—made familiar to me after many hours sat on her lap as she whizzed through puzzle after puzzle, humming and chomping on spearmint gum—is long and thin, always slightly italicized; there is something incredibly elegant about it. But the blue pen marks in the book resting in my mother’s hands were not this recognizable scroll, but rather harsh, jagged lines, many x’s and crossed out letters—the anxious weight of the pen pressed firmly against the paper, leaving deep indents like braille marks on the backs of the pages. Lines like anger. Like frustration. Like failure. I sat down next to my mother and realized her face was wet with tears. She flipped the pages slowly so I could see the compendium of jagged blue ink and blank white spaces among the black grids. “She’s never not finished a puzzle,” my mother said plainly and softly. “Where is she?” *Where is she?* I thought later, and often. As if she left. As if the invisible force of my Nanny’s disease had merely borrowed her for a while—leaving behind this monstrous body that was woefully temporarily incapable of making clues into words.

This ontologic aporia between physical presence and the evacuation of identity serves as a reminder of another facet of AD which plays a significant role in shaping the discourse surrounding it—its “invisibility.” Like Autism spectrum disorders and many types of mental illness, the symptoms of AD (especially in the early and middle stages of the disease) do not manifest physically, but rather behaviorally, and thus are not easily discernible by those who are not intimately familiar with the sufferer. Individuals suffering from invisible diseases always face undue stigma because culturally we expect pain and illness to be visible—a belief subtended by Modern Western occularcentrism. The privileging of the visual, and the suspicion and misunderstanding of those whose suffering is merely internal, is also a source of shame for Alzheimer’s sufferers which is replicated in AD rhetorics. For Diana McGowin (1994), who explicated her experiences with AD in the national bestselling memoir, the disease was especially difficult because she “looks okay” to those around her, and thus her cognitive impairments continually upset the status quo (McGowin 1994, p. 115). Soon after her diagnosis of Early-onset Alzheimer’s, McGowin gazes at her reflection in a mirror and comments “I looked perfect. I looked untouched. No one could tell just by looking at me that I wasn’t perfect

any more" (McGowin 1994, p. 74). As my own Nanny's condition worsened, my Auntie Margie (my mother's oldest sister) fought my mother for months on the decision to place her in a full-time care facility, often citing her "normal" physical appearance as evidence of her seemingly unchanged state. For sufferers of the disease and their loved ones alike, the unstable relationship between the outwardly unaltered body and the regression of interior cognitive function makes the disease at once less culturally resonant, and more personally shameful.

4. Intertextualizing Science

I move now to consider a sampling of contemporary scientific research surrounding Alzheimer's patients' language use and interpersonal communication. Using this data, I hope to illuminate how we might differently and more generatively understand AD sufferers' communication by an application of intertextual theory to their performances of memory.

First, I offer the biomedical explanation of the disease (and its relationship to dementia) to help situate my discussion in terms of this medicalized discourse. Dementia is a condition that is marked by cognitive or behavioral impairments in at least two of the following domains: "remembering new information, planning or completing complex tasks, recognizing faces or everyday objects, following and participating in conversations, and maintaining emotional stability and appropriate interest in daily activities" (Schrauf et al. 2014, p. 282). Alzheimer's disease is linked more explicitly with memory dysfunction and is marked primarily by the gradual onset (over years) of an inability to remember new information, plus one of the other inabilities mentioned above (Schrauf et al. 2014, p. 282). These deficits often lead to interactional problems including "conflict in relationships, social isolation and consequent feelings of frustration, depression and anger" (Kitzinger and Jones 2007, pp. 184–85). Confirmation of an Alzheimer's diagnosis is still possible only via autopsy, and identified by the accumulation of amyloid plaques in the brain, which leads to neuronal degeneration (Schrauf et al. 2014, p. 282).

Alzheimer's patients' loss of language and so-called "failure" of communication is well documented in the scientific community (Verma and Howard 2012; Minati et al. 2009), and has been explored both in terms of verbal fluency and naming (Chan et al. 1991; Auriacombe et al. 2006; Laws et al. 2007; Apostolova et al. 2008; Taler and Phillips 2008) as well as semantic fluency (Adlam et al. 2006; Clark et al. 2009). This literature identifies language impairment, including principal deficits in naming and fluency, as the prognostic marker of early stages of AD.

Despite the clear opportunity to consider Alzheimer's sufferers' deteriorating language use in terms of intertextuality, there has been little critical humanities work which does so. The singular existing study of this kind was conducted by Hamilton (1996) whose article, "Intratextuality, intertextuality, and the construction of identity as patient in Alzheimer's disease," argues for an intertextual approach to Alzheimer's patients' conversations as a means to conceptualize AD sufferers' identities as more stable and accessible than their language performance would initially indicate (Hamilton 1996, p. 61). She analyzes two conversations—taking place six months apart—between herself and a woman suffering from AD and performs both an intratextual and intertextual linguistic analysis in order to argue that the latter is a more useful heuristic for capturing the co-construction of patient identity for those with AD. Hamilton's work provides an invaluable critical foundation from which I proceed, but her use of discourse analysis stops short of doing the important work of reorienting our problematic ontologic conceptions of Alzheimer's patients' erased personhood, and elides important considerations of the intertextual nature of memory performance in AD sufferers, which, I argue, is fundamental for said reorientation. In what follows, I engage a subset of scientific literature which I believe provides a useful opportunity for the application of intertextual memory as a heuristic, as this literature does not consider not the deterioration of language skills and recall abilities, but rather tracks the adaptive linguistic strategies observed in Alzheimer's sufferers in their attempts to perform memory:

Images and Artifacts: In 2014, Brandao et al. conducted a study using eye-tracking software to determine the relationship between visual cues and linguistic competence in Alzheimer's patients. The study showed that if given access to pertinent images or other visual artifacts during conversation, Alzheimer's patients were able to compensate for linguistic deficiencies through the use of these visual cues (Brandao et al. 2014, p. 278). We can understand this work as underscoring the intertextual nature of memory because Brandao et al. found that when AD sufferers struggled to perform a specific memory through language alone, the introduction of visual artifacts (photographs, recipes, hand-written notes, etc.) increased the patients' ability to recall and narrate events. Thus, AD sufferers make explicit the intertextual nature of memory, which "lives" not solely in the realm of the linguistic, but is rather distributed across artifacts.

Music: There exists a plethora of studies showing that the use of music promotes successful memory performance for AD sufferers, and that even in the late stages of AD, many sufferers retain their ability to carry tunes and recognize melodies (Olderog-Millard and Smith 1989; Prickett and Moore 1991; Claire 2000; Tomaino 2002; Sacks 2007). Music is certainly part of the repertoire of intertextual memory. Ridder's 2003 study of the uses of music therapy for AD sufferers showed that by identifying and playing old music that was familiar to patients in their youth, these patients were able to narrate and remember stories they could not using language alone. Once again, this subtends an intertextual understanding of memory as distributed across an archive of texts and bodies.

Tense Shifts and Identity Substitution: In a 2008 narrative study by Heidi E. Hamilton (2008), she examines five tape-recorded conversations she has over the course of four years with an AD sufferer in her eighties, Elsie, and tracks Elsie's shifting uses of tense. Hamilton observes that these tense shifts often accompany narrative identity substitutions—wherein Elsie's "I" shifts and she "takes on" the identity of the person she was initially describing from her own subject position. (While Hamilton does not use Lee and Urban (1989) or Goffman (1979) conceptualizations, we might understand this shift of identity through Urban as Elsie's transition from using the indexical referential I to the anaphoric I while believing she is still using the indexical referential I, or through Goffman as Elsie animating narratives and experiences she believes she authored). Tense shifts and identity substitution thus represent adaptive strategies for narrating memories which rely on intertextual conceptions of identity (similar to Gell's "extended mind"). That is to say, by shifting narrational standpoints, Elsie is able to perform parts of her life from another's perspective which she does not have access to from her own.

What these brief interventions show is that intertextual understandings of AD sufferers' language, memory, and identity performances can reposition their communication not as failed, but as layered and adaptive. We might consider the ways AD sufferers' intertextual performances of memory mirror Levi-Strauss (1962) account of what he terms the *bricoleur*, who creates and invents "using devious means" and makes do with "whatever is at hand" (Levi-Strauss 1962, p. 8). Indeed, understanding AD sufferers not as failing to perform linguistic memory, but rather as succeeding in performing intertextual memory provides an alternative orientation towards AD sufferers' personhood, and creates ontologic possibilities for them that resist the erasure prevalent in cultural discourse.

In the summer of 2013, my mother visited my Nanny at Sunrise with my Auntie Sherry and my Uncle Ron just before my Auntie Sherry died of cancer. My uncle brought his guitar and the three sat around their mother and sang "Hey Good Lookin'" over and over to her for nearly half an hour. My uncle's rough fingers across steel strings in the same pattern. My aunt tapping her fingers on the table. My mother kneeling at her mother's side. Just before the end of the sixth rendition,

my Nanny—who has now lost all ability to speak and is confined to a wheel chair—opened her blue eyes wide and raised a hand towards my mother’s face (See Figure 1).



Figure 1. Personal photograph, 1 August 2013.

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