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Re-membering Daddy: Autoethnographic Reflections of My Father and Alzheimer’s Disease

Ragan Fox

This autoethnographic report chronicles communication-based interactions I had with my father after he was diagnosed with Alzheimer’s disease. Utilizing a modified version of Michael Fischer’s notion of “mosaic memory,” I construct a “mosaic” out of personal anecdotes about my father, scientific explanations of Alzheimer’s disease, and philosophical discussions of memory. The paper is an unconventional memorial to my father that provides a narrative blueprint for how other caregivers might respond to senility.

Keywords: Alzheimer’s disease; Autoethnography; Conversation; Memory; Metaphor

Dear Reader, I hate to spoil the story for you, but my Dad dies at the end. The tale of my father’s eventual death from Alzheimer’s disease is, in many ways, the cliché Alzheimer’s narrative. First, he forgets to fulfill promises. Then, he has trouble remembering my name. He spends 10 years failing to recall more and more details from his past; and then, one humid Texas summer, he dies. My apologies to Craig Gingrich-Philbrook, who rightfully challenges autoethnographers to write their reports “from temporal positions dislocated from the death-call” (305); but the theoretically provocative material will emerge with greater clarity if I work through the emotional mumbo jumbo at the start. I, therefore, begin at the end.

Most death narratives include a “death call.” Dad’s death call comes from my brother Leonard, the prodigal son and my father’s namesake. Leonard’s call arrives in the early afternoon of July 30, 2004.
“The nurse told me the next dose of morphine will be his last. I just thought you
should know,” Leonard whispers.

After Leonard informs me that my father is about to die, I remain surprisingly
calm. I thank my brother for his thoughtfulness, flip my annoyingly thin cell phone to
the “off” position, stick my iPod earbuds into my ears, and listen to Courtney Love at
the highest possible volume. My ears ring and fall numb as Courtney screeches on
and on about the perils of being a rock star. I bob my head up and down and
contemplate which one of my friends I will call first.

This should be when I cry, right? No tears! Where are the tears? Maybe, as a former
forensics competitor, I performed one too many works of literature in which the gay
protagonist receives the death call from a family member. I have rehearsed this scene
a million times in my head and performed the moment at university speech
competitions around the nation. I, the gay protagonist, get a phone call from a
mother, brother, or weird uncle about the death or impending “departure” of my
father. After two seconds of contemplative silence, I raise my sorrowed face, two tears
I try my best to fight back roll down my cheek, and, then, I crack a joke about my
father that tidily sums up the beautiful, heartbreaking essence of our relationship.
Where are my crying-through-the-tears tears? This is not a dress rehearsal. This is the
real thing. Alzheimer’s disease has robbed me of my Oprah-inspired “finding-my-
spirit” moment.

I suppose I have spent the last 10 years mourning the loss of my father. Each time
he forgot my name, I mourned. When he forgot to attend my college graduation and
said he never remembered being invited, I mourned. When he stopped eating solid
foods, I mourned. The tears I expect at the death call have already been spent.
I mourned a dying father so much that I have no idea how to respond now that he is
actually dead.

Reflecting on his father’s terminal illness, Jeremiah Dyehouse eloquently speaks to
the dying versus death conundrum. He writes:

What confounds me is the problem of learning how to love my father’s illness in its
specificity—his case, his response, his life. To love what is necessary, as Nietzsche
puts it, means in my case to love the illness that each day encroaches on his life.
I know that my father will die, and I know what the proximate cause of his death
will be. How am I to love his future and this knowledge? (211)

I ask the same question as Dyehouse: “How am I to love my father and his illness?”
I ask, because, after his diagnosis, the two became inextricably bound.

In this essay, I turn to narrative and autoethnography to self-reflexively consider
how I re-member my father, his illness, and the communication that took place
among care giving family members after Dad was diagnosed with Alzheimer’s disease.
I hyphenate “re-member” to underscore the multiple, sometimes disjointed memories
that comprise the overall memory I have of my father. I also hyphenate “re-member”
to stress the constructed-ness of my point of view as my subjectivity is expressed in
this essay. Narrative, after all, is as much a doing (Fisher) as it is a way of being
(Allison). While my experiences in no way bear a “burden of synecdoche” (Taylor,
“On Being” 70), or are meant to represent all Alzheimer’s disease care giving narratives, this autoethnographic account is intended “to stand with, not to stand in for, others’ stories” (Park-Fuller, “Clean Breast” 219). Ultimately, I ask, “What specific communication strategies help and hinder relationships between Alzheimer’s patients and their family caregivers?”

To answer this question, I begin by reviewing theoretical significations of memory as they relate to Alzheimer’s disease, autoethnography, and postmodernism. I then, employ narrative to reflect upon failed instances of care giving communication in my family. Finally, I argue that metaphors of death and destruction commonly referenced to describe Alzheimer’s disease should be abandoned in favor of a more productive analogue.

Metaphorical Understandings of Alzheimer’s Disease

The first time I hear the word “Alzheimer’s,” my young tongue trips over its distinctively German flavor. Do I hear a hard consonant between the “Al” and “himer” sounds? “Alt-himers?” Or is it, “Al-himers?” Maybe the woman on the news has a funny accent and is saying “old timers.”

Several years later, I pronounce the word with care and precision. My father has been diagnosed with the illness. I, upon hearing his diagnosis, “hit the books” and learn all I can about Alzheimer’s disease. Each fact reads like a different secondary school subject:

Period 1, History: The disease is named after Dr. Alois Alzheimer, a German neuropathologist who, in 1907, discovered the illness while conducting an autopsy of a disease-afflicted brain (Alzheimer).

Period 2, Science: Alzheimer’s disease (or AD) is a “degenerative disease of the brain” (Clarke 269; Bondareff). The illness characterizes a combination of multiple cognitive malfunctions that significantly impair a person’s ability to communicate. Diagnoses typically include mental deficiencies, including one or more of the following symptoms: apraxia, or decreased ability to execute desired movements; aphasia, or language impairment; agnosia, or an inability to recognize people and/or objects that were once familiar; and reduced capacities to plan, organize, and abstract (Müller and Guendouzi).

Period 3, Math: Alzheimer’s continues to significantly rise in incidence and prevalence. Roughly 10% of adults over the age of 65 and 50% of people 85 and older show symptoms of the disease (Clarke; Gatz et al.). Experts predict that roughly 15 million US citizens will have the illness by 2050 (Scinto and Daffner), a statistic that makes sense given medical and pharmaceutical technologies that have increased average age expectancies for men and women (Miller et al.). Alzheimer’s currently ranks as the most common cause of dementia (Katzman and Bick) and typically results in death 10 years after its diagnosis (Taylor, Alzheimer’s).

AD-related statistics and facts clarified my father’s situation, but the readings failed to address my emotional response to his diagnosis. When my father became ill, I turned to creative writing to help me work through my anger and sadness. This
would have pleased my dad, who earned a living as the author of a jewelry newsletter. Growing up, whenever we got into arguments, Dad retreated to his room and penned long, beautiful letters in which he explained his point of view and professed his fatherly love to me. He encouraged me to write, and kept large Rubbermaid boxes of all the notes my tiny, pink fingers slipped under his bedroom door. He even framed one of my messages and nailed it to a wall in his office! The framed letter includes faded words scribbled on the back of a letter-sized envelope and reads in broken cursive: “Your [sic] old and Im [sic] yung [sic]. One day soon you will die and all I want to do with my life is have fun. Plese [sic] let me go to the skating rink and TURN DOWN THE HEAT. Im [sic] hot!!! I love you!” In the bottom right corner of the letter, my father wrote, “Ragan, age 9.”

I was a late-in-life child. My father had me at 56, but for the first 12 years of my life, he convinced me that he was perpetually 50. Even at a young age, I knew he was significantly older than my friends’ fathers. The note my father framed and put on display indicates that, at age 9, I was keenly aware of my father’s age and mortality. My focus on his age and fear of his eventual departure was magnified by the absence of my mother, who left us when I was only a few months old. My father proudly boasted to be both mother and father to me. As a gay man, I know the metaphorical function of words like “mother,” “father,” and “family.” My dad taught me that these words are assigned by genetics but mostly earned through connection and communication. Aging and Alzheimer’s disease dramatically altered the connection and communication between my father and me. He would always be “Dad,” but, after he was diagnosed, darker metaphors began to emerge in my thoughts about him.

Much of my writing about Dad’s illness took the form of performance poetry. In these poems, I describe my father and his disease in every imaginable cliché. Poetic and scientific literatures are rife with many of the stereotypical metaphors I reference in my poetry. Authors (and I include myself in this critique) compare Alzheimer’s disease to “fog” (Rosenblum 51) and a mechanism that turns off multiple “light switches” in a person’s brain (“Alzheimer’s Disease”), and its sufferers to “missing people” (Clarke 274), left behind bodies (Whitehouse and George 23), and a “burning city” (Pierce 121). These metaphors, whether representative or misrepresentative, provide “additional information about the structure, content, and meaning” (Sackmann 465) of the disease. Throughout this autoethnographic account, I consider how metaphors constrained and enabled how I came to understand my father and his illness.

My love of narrative and involvement in communication scholarship greatly influence how I interpret my father and Alzheimer’s disease. Jonathan Silin’s book *My Father’s Keeper* inspired me to connect Dad’s illness to my career as an educator and researcher. In his touching autobiographical tale of providing care to his dying father, Silin frequently relies on his expert knowledge in the field of early childhood education to make sense of his father’s condition and treatment. Many caregivers utilize work experiences to provide care for elderly parents (Miller et al.). I, for example, reference communication and performance when talking about my father. One of my colleagues recently inquired about Alzheimer’s, and I, not surprisingly,
relied on communication metaphors to describe my father’s circumstances and my
family’s response to his AD.

“Alzheimer’s disease reminds me of a breakdown in communication,” I told my
friend Whitney. “The brain consists of billions of neurons that form a communica-
tion network. In Alzheimer’s patients, abnormal structures called plaques and tangles
form between nerve cells and inhibit the ability of neurons to talk to one another. The
process, in turn, limits a person’s ability to remember and communicate with people.”

“How is your family holding up?”

“Families are a lot like those neural networks I just described; and, in my family’s
case, Alzheimer’s is the abnormal structure that negatively affects our communica-
tion.”

Right after I developed the communication metaphor to explain Dad’s illness,
I began to document my observations in the hopes of conducting an autoethno-
graphic investigation. I turn to autoethnography in order to ground my recollections
of his disease in theory and to demonstrate how “meanings and significance of the
past are incomplete, tentative, and reversible according to contingencies of our present
life circumstances, the present from which we narrate” (Ellis and Bochner 745). I self-
reflexively consider the numerous mistakes I made as a son affected by his illness,
because others can learn from my missteps. Autobiographical accounts authored by
people familiar with the illness might help the rapidly growing number of men and
women living with the disease. Like other creative and autoethnographic reports
detailing how people cope with real and potential sickness (Dillard; Fox; Jago; Park-
Fuller, “Narration”), this study serves as a “narrative blueprint” that might inspire
“identification among audience members seeking a narrative model to help guide
future actions and behaviors” (Fox 8). Moreover, Elaine Wittenberg-Lyles advocates
the use of narrative in death and dying contexts because the practice “teaches
individuals to use story formats to provide instruction, prompt dialogue, and
enhance listening skills” (55).

When reflecting upon and reporting events from the past, I employ “conversa-
tional historical present tense” (Wolfson quoted in Langellier, “Two or Three Things”
131) in conjunction with past tense as an “internal evaluation device to structure the
story and heighten its drama” (Langellier, “Two or Three Things” 132). Conversa-
tional historical present tense dramatizes reenactments in personal narratives by
shifting from past to present tense (Langellier, “Two or Three Things” 131–132). At
times, I utilize a strikethrough (e.g. remembers remembered) to highlight heart-
breaking negotiations that occur when I mistakenly speak of my father in the present
tense. I developed this reporting strategy shortly after his death. After writing several
poems and performance pieces about him in which I accidentally typed verbs in the
present tense, I began to consider the performative import of typographically
highlighting my attempts to keep him alive in my writing. Dad, for example, loves
loved old Noel Coward and Gertrude Lawrence records. The initial phrasing is a
broken promise, a split-second moment when I earnestly believe Dad is a phone call
away.
I also employ “emotional recall” (Ellis and Bochner 752) activities as forms of data re-collection. Emotional recall specifies the process by which performers imagine being back in a scene by exploring its emotional and physical characteristics. Several emotional recall activities have been utilized in my study to help put “flesh” on the experiences I describe in this essay. Exercises included oral narrative tours of photos that feature my father; poetic dialogues in which I respond to journal entries I wrote about my father while he was in the midst of his disease; and shared oral narratives in which my siblings and I collectively recall events we shared with my father. Emotional recall exercises help me “move around in the experience” (Ellis and Bochner 752).

As a communication scholar, I regularly put my tools to the test when I visited my father. Emotional recall came in handy when prompting my father to remember significant details about our time together. He had a difficult time remembering my name, age, and city of residence. He seemed particularly forgetful when it came to my sexuality. Much to my gay dismay, he repeatedly asked me if I had met any nice, Jewish girls.

“Dad, we’ve been through this; I’m gay.”

I began to feel like the only gay man on the planet who had to come out to his father 556 times! Before my father’s diagnosis I was convinced the repetition of this question was Dad’s clever way of asserting his homophobia. When I understood the science behind his repetition, I, by way of emotional recall, discovered new ways to remind him of my sexual identity.

“Remember Ira,” I whispered to Dad. Ira is a former boyfriend my father met a few years before his memory problems materialized.

“Oh, yes. How is he? Are you two still together?”

Tactical use of memory prompts that took the form of people, places, and themes aided me in my quest to communicate with Dad. For AD patients and ethnographers alike, memory is a slippery beast. Philosophers and scholars have compared memory to prisons (Freud), religion (Margalit), computers (Bowman), and cultural mosaics (Fischer). M. J. Fischer’s conceptualization of “mosaic memory” is particularly useful when reflecting on the ethics of memory and ethnographic representation. Fischer argues that, “People increasingly construct their sense of self out of pieces that come from many different cultural environments” (82). This process layers memory into “differently structured strata, fragmented and collaged together like mosaics in conscious and unconscious maneuverings” (Fischer 80). The mosaic metaphor speaks to how the parts (i.e. seemingly disparate memories) and whole (i.e. unified memories, or memory) of human recollection work concomitantly to frame understanding and shape interpretation. In other words, a mosaic is nothing without the tesserae, or component pieces, that comprise the “big picture.” My father’s understanding of the “bigger picture” of my sexuality, for instance, depended on his ability to connect disparate people, places, and themes. Stressing memory’s mosaic qualities situates human recollection as partial, citational, fractured, de-contextualized, re-contextualized, reflective, refractive, decorative, and text-ured. The following section chronicles my reliance on the mosaic metaphor to help refine and interpret conversations between my father and me.
Using Conversational Mosaics to Improve Communication with and about AD Patients

My father had six children, and none of us lived in the same state (so to speak) as my father. Most of us abhor Texas, which helps to explain why each of us lived far away from Dad. Our stepmother Joyce became Dad’s sole keeper. Joyce assured us in numerous phone calls that Dad was doing “okay,” “fine,” and “delightful.” Many primary caregivers, like Joyce, see themselves as the only person capable of taking care of a loved one who has Alzheimer’s disease (Miller et al.). This is not to say Joyce’s assurances provided sufficient reason for any of Dad’s children to be inactive in the planning and execution of his care. I, personally, never wanted to sit down with Dad and talk about his waning health and memory. Having grown up during the Great Depression, my father had a tendency to focus on the promise of better times. Mortality was never a topic of discussion in Dad’s house. He never mentioned death, wrote a will, or entertained the possibility that he would ever be ill enough to stay in the hospital for an extended period of time. Hospitals made him anxious, so we avoided having conversations with him about his deteriorating condition.

Ironically, conversation played a central role in how I came to know my father and understand his disease. Narrative also plays a key role in perceptions of death and dying, because death narratives influence how terminally ill people and their caregivers communicate (Wittenberg-Lyles). In this section, I use narrative to investigate what conversational and interpretive strategies might improve communication between family caregivers and Alzheimer’s patients. First, I consider how my father’s conversational patterns function as conversational mosaics. I then, posit that competing memories of and stories about my dad constitute a mosaic memory.

My Father’s Strategic Use of Conversational Mosaics

The year is 2003. I call my father. “What’s new and exciting?” Dad asks with the enthusiasm of a game show host.

“Oh, no,” I think to myself. Another round of the “new and exciting” dance, a repetitive and spiral-filled tango in which my father continuously spins his way back to the question, “What’s new and exciting?” I take my father’s hand, and his disease takes the lead.

“Anything new and exciting?” he repeats.

“Not really, Daddy,” I explain. “I’m teaching and finishing up school.”

“Where are you living these days?”

I hate this question! I have lived in the same city for almost four years. Why bother talking to him if he refuses to remember simple details?

“Phoenix, Daddy. I live in Phoenix.”

“Phoenix? Really? What’s new and exciting in Phoenix?”
“I’m going to try to quit smoking,” I reply, searching for any reply that will answer the sphinx’s riddle: “What’s new and exciting?”

“Good! You should do that, Rago. Quit smoking. What else is new?”

“That’s about it, Dad.”

“Nothing new and exciting?” he asks more flatly this time around. Each repetition of the question loses a bit of the previous attempt’s joy. Each subsequent time he asks me about the “new and exciting” events in my life, his voice becomes lower in pitch and increasingly broken and glum. My father’s morose intonation intimates that he is aware of his illness.

Dad’s dependence on the phrase “What’s new and exciting?” is consistent with many Alzheimer’s patients’ ability to engage in formulaic and socially polite communication (Rhys and Schmidt-Renfree). Patients also adhere to the “structural norms of conversational behavior such as turn taking” and providing answers that “satisfy the requirements of the question” (Rhys and Schmidt-Renfree 537–538).

Many AD patients retain understandings of the structural level of communication but have difficulty comprehending the substantive or content level (Hamilton). Dad knows how to perform greet, smile, and friendly question, but he cannot recognize substantive cues spoken by other people located “onstage.” Of course! This is all a performance. My father, the man who introduced me to musical theatre and the dramatic arts, is performing a normal conversation. “What’s new and exciting?” acts as a structural backbone that gives form and balance to otherwise shapeless and content-deficient exchanges. This conversation filler also functions like “muscle memory,” or our body’s ability to subconsciously engage in activities after several repetitions. And who knows the importance of repetition in memory retention better than a performer?

I also propose that his ability to communicate, however limited, might be better understood in terms of a mosaic. My father pulled pulled tesserae, or a mosaic’s component pieces, from past experiences and pasted the fractured bits together to have conversations that might pass as normal. Portions of Dad’s conversational mosaic include adherence to many of the structural norms of conversation, specific memories he was able to recall in a given moment, and emotional cues. Had I paid more attention to the interpretive process while conversing with my father, our conversational topics may have been less repetitive and he may have appeared less “defeated and glum.” Creating a new relationship that focused on an abdication of the immediate past and a “commitment to live in the moment” (Bergman 30) might have significantly improved our communication and my father’s state of mind. The mosaic metaphor can be used to help other caregivers better interpret and navigate conversations with Alzheimer’s patients. Previous research indicates that many family caregivers become frustrated and uncommunicative when faced with AD-related repetition and forgetfulness (Miller et al.). Repetition may be read as a cue for caregivers to become primary storytellers in an exchange, or redirect the conversation to another topic, time, person, or place. Redirection might allow Alzheimer’s patients to access more pieces of new conversational mosaics.
Referencing Daddy, Referencing a Mosaic

Many of the recall activities I employed in preparation for this essay involved having conversations with friends and family members about my father’s history. Pictures of and journal entries about my father prompted conversations, and these dialogues challenge all I thought I knew about my father. The stories I heard about him lack a sense of “fidelity” (Fisher 8), meaning they do not “ring true” with tales that Dad told me about himself. The more others tell me about my father, the more I question my proficiency in a subject I thought I had mastered: History of Dad.

For the following questions, bubble in the BEST possible answer.

<table>
<thead>
<tr>
<th>True</th>
<th>False</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(1) My father went to Pennsylvania State University.</td>
</tr>
<tr>
<td></td>
<td>(2) Dad’s mother was a nurse in the hospital in which he was raised.</td>
</tr>
<tr>
<td></td>
<td>(3) Daddy has never gone to prison, nor has he engaged in sins of omission about the subject.</td>
</tr>
<tr>
<td></td>
<td>(4) He was married five times to women named Nola, Betty, Gay, Jodi, and Joyce.</td>
</tr>
<tr>
<td></td>
<td>(5) After Dad became untied, his lies were exposed, one by one.</td>
</tr>
<tr>
<td></td>
<td>(6) My sister’s lips let the first sin slip: Dad spent time in jail for a white collar crime.</td>
</tr>
<tr>
<td></td>
<td>(7) When I mention my dad’s five wives to a family friend, she replies, “You mean six. Your father was married six times.”</td>
</tr>
<tr>
<td></td>
<td>(8) Documents prove that my grandmother was a cafeteria worker in a hospital.</td>
</tr>
<tr>
<td></td>
<td>(9) My brother’s wife confides in me that she doubts that my father went to college. No objects exist to rebuke her claim. No stains of university life can be found in what Dad left behind. No degree. No receipts. No class ring. No photo. No evidence to bait me into defending his honor, his memory, his life story. No evidence to triangulate his narrative. No indication Dad told it straight. No record of him at Penn. State.</td>
</tr>
<tr>
<td></td>
<td>(10) All the new truths make me feel like a torn scantron, like a dull eraser has worn away every memory about my father that was once marked “true.”</td>
</tr>
</tbody>
</table>

Dad, a child of the Great Depression, may have thought that manipulating his past would give him access to contexts that would improve his future. He treated his past like a narrative mosaic, setting truths next to lies. Standing in close proximity to the picture Dad pasted together reveals fractures and incongruities; but a little bit of distance transforms his craftwork into a seemingly coherent and unified portrait of a man. Growing up, Dad’s creative reshaping of history lies were true to me, regardless of whether or not his mother was a nurse or he attended Pennsylvania State University. The lies and sins of omission exemplify “double-negativity” (Schechner, Between Theater 110); they are not true, but not-not true.

Competing notions of my father’s identity were made all the more confusing for members of my family, because, on occasion, Dad had sudden moments of clarity. This back-and-forth, double performance of identity—between senile and lucid—proved
particularly devastating and confusing, as it created a double consciousness of
performance for my father in which all his speech acts were “placed in mental
comparison with a potential, an ideal, or remembered original” of who he was and
might be (Carlson 5; see also Bauman). My witnessing of this was primarily relegated
to phone conversations with my father. One, in particular, stands out in my mind.
Joyce puts Dad on the phone. He is surprisingly pleasant and lucid. A long-
forgotten grin travels through 1500 miles of phone line. His smile sizzles west,
sparking wires that cut across dust bowls and sand storms. His upturned lips and
joyful, lilting cadence are electric. Synapses fire and ignite the sky.
“Ragan?” (He remembers my name!) “How’s life in Phoenix?” (And the city I live
in!)
“Things are great, Dad. You sound like you’re having a good day.”
“I am, but let’s talk about you. Are you seeing anyone? How’s school and work?”
Tears rush to my eyes and burn them rose red. Dad listens intently as I describe the
mundane events of the last week. After I finish telling him about a recent date with
the latest frog I failed to transform into a prince, I await the query, “What’s new and
exciting?” Dad responds, “Don’t worry, you’ll find a great man soon enough.”
Suddenly, Dad is back! Back! Back from the abyss! Back to scratch my back, like he
did when I was his little boy, his “wee tot.” Back!
Roughly ten minutes into reveling in the return of my father, he interrupts my
train of thought. “What’s new and exciting in, in, in . . .” he asks, searching for the
name of the city where I live. “. . . in, in, in—”
“—Phoenix, Daddy; I live in Phoenix.”
I spend the following few months myopically focusing on his brief moment of
lucidity. “Can you believe how much better Dad is doing,” I say to my sister in a more
declarative than inquisitive manner. “Dad’s doing great! We had the best conversation
on the phone a couple of weeks ago,” I tell my brother Leonard.
Time and again, I relied on conversational strategies to downplay the severity of my
father’s condition, shirk responsibility for his care, and justify all the “missed
evidence” (Ridge et al. 149) of his disease. These tactics included gossiping about his
past, placing too much emphasis on his rare moments of lucidity, and assuming his
wife provided sufficient care for him. Conversations about Alzheimer’s patients
sometimes inhibit and sometimes promote shared care giving among family
members. Competing realities of the patient that may emerge in conversations about
him or her constitute a mosaic memory of the loved one. Members of my family
stressed the importance of a few mosaic pieces over others when justifying care giving
strategies, or a lack thereof. Understanding an AD patient’s identity in terms of a
mosaic may help other caregivers as they attempt to reconcile competing
conceptualizations of their loved one’s identity, personality, and personal history.

Lessons Learned at Dad’s Hospice Home
I enter my father’s floor at a hospital that caters to the specific needs of Alzheimer’s
patients. The doctors tell me that Dad has come here to die in comfort. Dad had no
say in this decision. One day, Joyce admitted him without asking for the input of his six children. I wish that I, along with other family members, had sat down with my father and engaged in an uncomfortable and emotional conversation about his illness. Alzheimer’s strips patients of agency as much as it does memory. Had we sat down with my father when he was in the early stages of the disease, we could have asked him what he wanted in terms of care. I, therefore, agree with Miller et al., who suggest that “living wills” for Alzheimer’s patients should be “expanded beyond end-of-life decisions to include care decisions as well” (37).

As I make my way down a hall that leads to my father’s room, I sneak peaks into the rooms of other patients. None of them resemble my father. Time spent in the hospice facility with Dad helps me comprehend why I, in the early years of his illness, spent so much time denying that he had Alzheimer’s disease. Because Alzheimer’s characterizes the presence of any combination of a long list of possible symptoms, denial of the disease might be justified or performatively rendered meaningful by an alternate list of all the indicators not present in a person’s loved one. Affirming by the negative is how I denied Daddy’s disease. I myopically focused on all the symptoms of Alzheimer’s he never had. Alzheimer’s is a mosaic disease, because individual indications of the illness are akin to tesserae in a mosaic. A person’s ability to see the “bigger picture” of AD depends upon his or her willingness to join the pieces. Because different patients demonstrate their own unique hodgepodge of symptoms, individual patients’ mosaics may appear significantly different.

Walking through the hospice home, I take note of how radically different my father’s AD is from his cohabitants. The patients are an amalgamation of presence and absence, which is Alzheimer’s Cliché #16. Some look at me but do nothing to verbally or nonverbally communicate that they see me. Alzheimer’s Cliché #23: Glassy eyes stare through me. Men and women in the home exemplify Alzheimer’s Cliché #14: They appear caught between life and death. They remind me of zombies, which, in my book of poetry, is Alzheimer’s Cliché #1.

The year is 2004, and Hollywood has made a killing off of zombie films. “Zombie” is a cruel, stereotypical metaphor that obscures the complexity of Dad’s disease; but this metaphor provides an in situ example of how my brain made sense of the patients in Dad’s hospice home. Dehumanizing other AD patients is how I affirm by the negative.

My Dad is not catatonic. One man lies in bed in a perpetual state of catatonia. His frail body has been reduced to ashy skin wrapped tightly around brittle bones that look more like matchsticks than skeleton. His mouth hangs agape and head cocks to the right as he stares outside; his eyes do not move.

My father does not hallucinate. An older, short and thin woman wearing fire engine red thermal pajamas greets me as I continue down the halls of the hospice home. She
smiles at me and claims to regularly talk to Santa Claus. Unlike the catatonic man staring into an abyss, the patient standing before me appears vibrant and colorful. Minutes later, a nurse informs me that the woman has been sneaking into my father’s room and throwing his pictures and keepsakes into the garbage.

Quintessential zombie film scene:

A major character—usually a best friend, mother, or father—is bitten, and, despite the inherent danger of not declaring the bite, he or she conceals the wound and denies inevitable doom.

Daddy does not know how to call for help. Two doors down from Dad’s room, a zombie I do not see punches S.O.S. into a call button. (Beep.) “Help me,” (beep) the man groans in a husky and broken baritone. (Beep.) “Help.” (Beep.) A light above his door flashes pale yellow each time his thumb presses down on the button. But the nurses at the station know all the zombie wants is a “fresh brain,” so they stay far away. “Do they ignore my father’s calls, too,” I wonder.

When the movie becomes too intense,

I hop downstairs, bang on Dad’s door, and cry.

He convinces me that zombies are the stuff of movies and we don’t live in fiction.

I stand at his door, and knock three times. As I enter the room, Dad’s eyes brighten and lips turn up in a half-cantaloupe grin. He greets me with a, “Hello, my love.” He has lost so much weight! It looks as if somebody stuck a pin in Dad’s skin and deflated him. He looks skeletal.

“Hello, Daddy. I’ve missed you.”

“What’s new and exciting?” he asks in a strained voice.

“Being here with you, Dad. That’s what’s new and exciting in my life. How are you? Do you like it here? Is there anything I can get for you?”

“No, I’m fine. I want to hear about you. What’s new and exciting?”

And, so, the dance begins again.

Dad’s facial expressions add texture to the repetition. With each new, “What’s new and exciting?” I notice an utter look of defeat and frustration in his face.

“What’s new and exciting?” → upturned, enthusiastic smile slips to:

“What’s new and exciting?” → corner of right lip quivers and begins to collapse, which leads to:

“What’s new and exciting?” → both ends of his lips have given way to the weight of an apparent self-awareness that he’s repeating:

“What’s new and exciting?” → glassy tears rush to the bottom lids of the baby bluest eyes I have ever seen, but I still get another:

“What’s new and exciting?” → yesterday’s Dad is trapped inside our mind and aware of so much that has been forgotten. His eyes know the lies of his lips’ repetition. He understands the machinations of zombie films; and that, for me, is the most heartbreaking characteristic of Dad’s disease.

The last thing I do for my father before our conversation ends is wipe blood from his forehead. He has a scab at his hairline. Every few minutes, he picks at it. “Dad,”
I chastise, “stop picking; you’ll dig a hole straight to your brain.” He closes his eyes, crosses his arms over his chest, and takes a nap. Silence fills the dark, sterile room. I spend a few moments reflecting on my visit.

I am not proud of comparing my father and other people at the hospital to zombies. Describing AD patients as the “living dead” is a stereotypical characterization that belies the complexity of Alzheimer’s disease and the humanity of its sufferers (Bergman). I chronicle my use of the metaphor in this paper, because it repeatedly emerged in the poetry I wrote while my father was in hospice care. Inhuman metaphors are also “in vivo terms” (Lindlof and Taylor 219–220) that many AD patients utilize to describe themselves. Ridge et al., for example, chronicle the story of an AD sufferer who told her psychiatrist that she wanted “to be like a human again” (155). I also write in terms of the metaphor to stay true to how I encoded my relationship with my father as his health declined.

I said and thought a number of ridiculous things while my father lay in his hospital bed. At one point, I remember telling a friend that I wished my father had cancer, because, at the time, I believed cancer would have been easier for him. I had forgotten that I made the horrible comment about cancer until a student in a graduate seminar I taught in the fall of 2007 performed a personal narrative about his grandmother’s struggles with Alzheimer’s disease. His piece, titled “Why I Wish My Grandmother had Cancer,” triggered a number of memories about my father. The narrative incited me to self-reflect on how metaphor and other comparisons performatively shape comprehensions of Alzheimer’s disease and affect communication practices between patients and their loved ones. Metaphors, especially those introduced by the medical community, function as tesserae in mosaic understandings of illness. The analogues have performative ramifications for the way people make sense of AD and treat Alzheimer’s patients. Metaphors of death and destruction prove less than productive when trying to enrich communication between caregivers and Alzheimer’s patients. In Illness and Metaphor, Susan Sontag eloquently speaks to the punitive implications of describing diseases by way of metaphor. She writes that, “Any important disease whose causality is murky, and for which treatment is ineffectual, tends to be awash in significance. The subjects of deepest dread (corruption, decay, pollution, anomie, weakness) are identified with the disease” (57–58).

Metaphors of destruction and disappearance weigh heavily on my mind as I consider the likelihood that I, too, will become an Alzheimer’s patient. Studies show that genetics play a significant role in the development of Alzheimer’s. The presence of AD in a person’s genetic history both increases the possibility of Alzheimer’s (“Heredity”) and, in some cases, plays a deterministic role, “guaranteeing that anyone who inherits [the genes] will develop the disorder” (“Causes”). My fears ignite when I hear my father stumble over names. They grow stronger each time I talk to my mother about her own father’s battle with the disease. “All sons turn into their fathers,” I have heard friends say. Looking into my father’s eyes, I see a familiar blue.
Sitting Shiva

Thunder rolls into Houston the day we bury my father. Lightning tears through the damp August sky, causing black and brown birds to fly from power lines that pinprick the earth at Dad’s new resting place. Power line posts eerily resemble crosses. I try to keep my focus on the birds, sky, and posts—anything to keep from looking at the small pine casket that holds my father. After a few extended minutes of holding back tears and averting eye contact, I stare at the box, perplexed by its diminutiveness. How did they manage to fit my father in something so tiny? They must have broken his legs! I wonder what else they did to sculpt his body into its death pose. Did they painstakingly sew his lips into a smile? He must be hot in there. That box must feel like a microwave oven.

“This is it,” I think to myself. “He’s gone. No more Dad. Fathers Day, nevermore. No more calling for advice; no more sound of his voice. Dad does not feel hot in that box, because he does not feel anything. He is dead. This is not a dress rehearsal. This is it.”

I teeter side-to-side; tears eclipse the lenses of my eyes. I need something to focus on. Repetition reminds me of all the parts of Dad that his illness left alone, all the tesserae that have been re-shattered, (re-)claimed by memory, and held hostage in my brain.

This is it.

His jovial, baritone voice slips into an echo existence.

This is it.

Dad’s musky scent slowly fades away from his favorite shirt.

This is it.

No more movie musicals sung together.

No more Best Little Whorehouse in Texas, Victor/Victoria, and My Fair Lady.

This is it.

No more nudging my chin against the small sunburn bumps on his chest.

This is it.

With Dad gone, who will ask me what is “new and exciting” in my life? Who will care?

Since his death, I have spent years studying his mosaic, trying my best to determine which fractured bits of memory best represent his essence. In this essay, I have written against and through an oscillating tension between lived experiences with my father and a dad who has been reconstructed as an object of study in this report. This ongoing back-and-forth between “being there” (i.e. laying my head on Dad’s lap as he drives down winding city streets) and “being here” (i.e. theorizing my father’s disease) has allowed me to consciously “I-witness” (Spry 706) the (re-)construction of my father. This way of conceptualizing memory and narrative is similar to Schechner’s belief that recollection is not a direct reflection of the past but what is “encoded and transmitted” (“Collective” 43). Re-telling an event creates a form of truth but does not stand in for the truth of the event as it transpired (Langellier,
Perspectives on Theory” 270; see also Lockford). In addition, personal stories rely on a montage of embodied memories that do not “call selves into existence so much as [they call] them into significance” (Pineau 45). This study is, in part, a call for autoethnographers to write more about memory in their work. Examples of this self-reflexivity include philosophical discussions that detail how ethnographers remember events; innovative typography that highlights how memory is fractured and subjective; and more applications and extensions of the mosaic metaphor to articulate the complementary and contradictory functions of memory and representation.

Autoethnography’s focus on the individual is precisely what makes its considerations of memory particularly important and heuristically provocative. While preparing for this report, I had a surprisingly difficult time finding autoethnographic essays that explicitly and philosophically address issues of memory recall. I say “surprising,” because memory has played a central role in the history of Western thought and is one of the five classical rhetorical canons. The ways in which I apply Fischer’s conceptualization of mosaic memory to ethnographic research may prove useful to scholars invested in the compositional structure of memory. Fischer’s theory demonstrates how juxtapositions of memory’s component parts shape understandings of people, events, and discourses. The mosaic metaphor, for example, highlights the contingent and synecdochical parts that comprise my father’s overall composition.

The study may also be utilized as a “narrative blueprint” (Fox 8) for anyone who anticipates being or is currently the loved one of an Alzheimer’s patient. A few lessons can be gleaned from my experiences. First, I recommend talking to an Alzheimer’s patient about future care before he or she becomes too incapacitated to make decisions. This is a difficult but necessary conversation. A number of heartbreaking arguments could have been avoided had my family done more than merely guess that “this” or “that” was what my father “probably would have wanted.” We each pulled from different memories to justify our competing points of view. Retroactive sense making diminishes an Alzheimer’s patient’s agency and contributes to breakdowns in communication among his or her caregivers. Pro-active communicative approaches address these concerns head-on.

Second, metaphors employed to make sense of the illness tend to shape communicative exchanges among Alzheimer’s patients, their friends, family members, and caregivers. The zombie metaphor that I reference in this paper negatively affected how I interacted with my father and perceived other patients at the hospice home where he eventually passed away. Discovering new metaphors to describe AD should be of central importance to communication scholars and healthcare professionals, as metaphorical depictions of other widespread diseases like HIV have been shown to influence a patient’s quality of life and treatment by cultural members (Norton et al.; Bird; Brouwer).

Inasmuch as metaphors manipulate people’s conceptualizations of Alzheimer’s disease, metaphors also help govern the autoethnographic project. By advocating a more self-reflexive consideration of memory in autoethnography, I hope to continue
and in some cases begin conversations about how events are recalled and discussed in research reports. My father’s struggles with Alzheimer’s have inspired me to think about memory in new and productive ways. Writing this essay was an exercise in remembering and a ritual of mourning. Mosaics we build in our research do more than help readers understand communication, they memorialize.

References


