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INTERDEPENDENCE WITH OUR MOST FORGETFUL ELDERS:
ALZHEIMER'S IN THE ANTHROPOCENE

A Dissertation

Submitted to McAnulty College and Graduate School of Liberal Arts

Duquesne University

In partial fulfillment of the requirements for
the degree of Doctor of Philosophy

By

Christine Heller

August 2021

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Christine Heller

2021

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ALZHEIMER'S IN THE ANTHROPOCENE

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ABSTRACT

INTERDEPENDENCE WITH OUR MOST FORGETFUL ELDERS: ALZHEIMER'S IN THE ANTHROPOCENE

By

Christine Heller

August 2021

Dissertation supervised by Dr. Russ Walsh

This dissertation uses autoethnography and critical psychological and philosophical theories to explore what people with Alzheimer's disease teach us about being, forgetting, and dying in the Anthropocene. The author collected personal memory data from her lived experience of being with her mother while she had Alzheimer's disease, and organized these memories into a series of vignettes. Each vignette was analyzed with critical psychological and philosophical theories to illuminate intersubjective themes of denial, things, ancestors, place, dying, and time. These themes connected the personal to the epochal and articulated the wisdom that our most forgetful elders can share in the Anthropocene, an era that reproduces itself around the fulcrum of forgetfulness about the interdependence of humans with the rest of the biosphere. A number of themes emerged which were elaborated in the form of wisdom being passed

down from our most forgetful elders, including: denial is part of the journey, and needs to be worked through; listen for the animacy of things and other beings; you can call upon your ancestors for support and guidance; did you know that you can time travel?; agency in death is difficult to discern; be a steward of chronic grief; and care is political. It was found that our most forgetful elders remind us of our interdependence and show us ways of resisting capitalist and colonial ontological pressures, which in turn can help us navigate the climate chaos brought about by the Anthropocene.

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This dissertation is, in its entirety, an attempt to acknowledge my gratitude and love for my Mom, who shaped my belonging to the world. Her lessons have guided me along the way, and the wisdom she offered during her season with Alzheimer's disease is the gift I aim to share through this project. Thank you, Mom.

I want to express my deep gratitude also to:

My Dad and my Brother. I feel lucky that going through this experience with Mom has only brought us closer together.

My partner Kyle, who has become my home.

My therapist Denise, who helped me trust my experiences of my ancestors.

My dissertation committee: Russ, Eva and Elizabeth, whose guidance was generative and trusting.

My PhD cohort: Sadie, Kate, Tricia, Autumn Marie, Sean, Luigi, and Adina, who grounded me even in the most abrasive winds of the last 5 years.

My friends, including Dorothy, Maayan, Michelle, and Matt, and so many others, who have been right there with me during the hard times and the playful times alike.

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Memory is a strange bird
doling out the world in

shards –
the stuff we are made of.

I am the keeper, now,
I hold them all.

Tonight as I write I become conjurer –

when I open my hands:
a thousand sparrows

– Jessica Moore, *Everything, Now*

Chapter 1: Introduction

This study investigates sharing a lifeworld with my Mom¹ while she had Alzheimer’s disease, within the sociohistorical context of the Anthropocene. My interest in the topic of this study arose from my experience relating to my Mom while she lived with Alzheimer’s disease, and my dissertation is an ode to her in many languages—personal, psychological, and philosophical. It is an ode to the persistence and evolution of our connection and how we both related to broader cultural systems as she transformed with the progression of the disease. As her ways of being in the world morphed through the course of her illness, she shed light on what it means to be a person living through the Anthropocene. Her shifting subjectivity revealed wisdom about being, forgetting and dying in this present epoch, gifts of wisdom that provided a unique perspective on the mutually-reinforcing reproduction of subjectivity and collective historical lifeworld. This dissertation aims to articulate these gifts through a series of stories based on my memories of being with her through the course of her disease, alongside explorations of critical psychological and philosophical theory which seek to elaborate on the broader implications of these stories.

My Mom, Linda Heller, progressed from having Mild to Major Neurocognitive Disorder due to Alzheimer’s disease over a period of 6 years, and she died from the disease in April of 2019. As her daughter, I strained to stay in contact with her spirit, something that required a steady stream of acknowledging and grieving the small but persistent and accumulating changes

¹ I use the term “Mom” rather than “Mother” because this project prioritizes intimacy over so-called “objectivity,” which often confuses disconnection for truth.

and losses, and celebrating our new forms of relating and co-existing along the way. As Alzheimer's disease morphed our shared lifeworld, she became foreign to my recollection of her, the threads of her memory unwinding from our shared world and weaving another way of being in the world.

This dissertation is an autoethnography, exploring my embodied relational connection to my Mom in the context of our cultural situatedness. Autoethnography is a qualitative research method that explores personal experience in relation to wider cultural, political and historical meanings and phenomena, and offers an evocative, embodied perspective from which to describe and critique the wider cultural dynamics. I draw upon existential phenomenological methods of interpretation to explore how my Mom and others with Alzheimer's disease may experience their lifeworld transforming, attending to themes like dwelling in a place, being in time, relating to things, and to other beings, human and other-than-human. My primary research question focuses on what people with Alzheimer's disease can teach us about being, forgetting, and dying in the Anthropocene, an era of deep, collective forgetfulness about our interconnectedness with human and non-human beings. I weave this all together using a distinctive method of autoethnographic research by using a series of personal recollections about my relationship with my Mom, followed by theoretical explorations of those stories, a method I will describe more in depth in the method section below.

Why situate my project in the Anthropocene? The Anthropocene is perhaps the largest scale systemic structure under which our daily lives are organized on a global level. The concept of the Anthropocene, which will be more thoroughly defined later in this introduction, articulates that humankind is the most powerful force shaping the vast ecosystems across our planet for the last several hundred years. It correlates with and subsumes other vast systemic structures, such as

capitalism and colonialism, that shape most contemporary cultures. Importantly, its influence structures subjectivity in ways that will be explored throughout this dissertation. I chose to frame this dissertation within the context of the Anthropocene because it frames and drives the most significant existential threat that humankind has ever faced, as we continue to shape the planet in ways that make it ever more inhospitable to our own survival. The Anthropocene reproduces itself out of a dynamic of a seeming forgetfulness about our interdependence, and instead supports domination and objectification as primary relational structures. Despite longstanding observations about the negative impact of human domination of the biosphere that have been practiced over the last half millennium, modern life is organized by “systems of governance that generate structural forgetfulness about injustice, destruction and despair” (Collie, 2019). This dissertation asks what our most forgetful elders might teach us about forgetting, being, and dying – important themes to investigate in understanding how and why we continue to perpetuate the Anthropocene, and how we might survive it.

The topic is challenging to study for many reasons. It can be difficult for people with Alzheimer’s disease to describe their experience such that someone else can understand, especially because aphasia (difficulty speaking) is a common symptom of Alzheimer’s. I am therefore vigilant in trying not to speak for, or over, the personal narratives of people living with Alzheimer’s disease. Because I am not living with Alzheimer’s disease myself, I am sensitive to the ways I might be able to approach some understanding without presuming I’ve got it right. My methods of exploration therefore privilege this conundrum, by situating my research autoethnographically—that is, based in *my* experience of relating to my Mom while she had Alzheimer’s. Another challenge of this project is catching sight of how the Anthropocene, the largest systemic structure we are under, has impacted my lived experience. The Anthropocene

can be hard to articulate in daily life because it is the water we are all swimming in. Furthermore, distinguishing characteristics of the Anthropocene from characteristics of other large systems such as capitalism, or United States culture, is not always clear or even possible. This project is therefore a way of thinking into the forgetfulness of the epoch, pushing at the edges of my own understanding.

Because this project is based in my experience with my Mom, it is important that my readers know a few things about me and my social identities. The experience I had with my Mom while she had Alzheimer's disease is not intended to be representative of others' experiences, and my cultural situatedness and role in caring for my Mom are important contextual factors. My situatedness is important for readers to keep in mind, because I undoubtedly hold biases and have blind spots due in part to how I was socialized. I am a 33-year-old, white, queer, able-bodied, cisgender woman, and I grew up with considerable class privilege that has, along with my whiteness, been a major factor in my being able to access an abundance of educational opportunities, including my current pursuit toward a PhD in clinical psychology. I grew up in urban centers in the Pacific Northwest, mostly in Seattle. My Mom was a white, heterosexual cisgender woman born in 1946 who grew up in a small fishing town in Alaska and lived most of her adult life in Seattle. She experienced upward class mobility and was able-bodied for most of her life. My Mom and Dad remained married until her death in 2019, and my Dad was her primary caregiver during the many years she had Alzheimer's disease.

My Dad saw a different side to my Mom's experience of Alzheimer's: the daily caregiving side, which was undoubtedly more challenging and exhausting, and probably a great deal less romantic than the perspectives I share in this project. If there is an unsung hero in this dissertation, it is my Dad, whose dedication to my Mom's wellbeing at the end of her life was

core to his identity for a number of years. He did right by her throughout an impossible time in our family. I describe myself and my older brother as secondary caregivers, because we were both living in different states from our parents during the time my Mom had Alzheimer's. As a result, we were only occasionally involved in the daily care for my Mom whenever we could visit, every few months. Despite the distance, being with my Mom while she had Alzheimer's disease was primary in my experience for the years during which she had it. Navigating graduate school at the same time was a difficult season in my life, and part of how I made space for my grief amidst the grueling workload of a PhD program was by using the space of my studies and research to engage with it. This project is therefore the culmination of many years of exploration.

Through this project, I hope to contribute a more robust understanding of being in relation to loved ones who have Alzheimer's disease, to offer language to the experiences of intersubjectivity that can deeply alter our own perception of what it means to navigate death and life in the Anthropocene, and more specifically within a Western neoliberal cultural context in the United States. I anticipate that my project has the potential to impact various perspectives from practical to philosophical. Practically, I hope that my project will influence how we care for our most forgetful elders by illuminating the definitions of selfhood that motivate our styles of caregiving and understandings of interdependence in the Anthropocene and the Western colonial and capitalist structures that have shaped our practices of care. Philosophically, I aim to contribute to our understandings of intersubjectivity and selfhood, and the ways in which memory can reinforce or challenge dominant structures of subjectivity under the conditions of the Anthropocene. Personally, this dissertation has been one of the ways I continued to stay in relation to my Mom after her death, and I attempt to remain faithful to my lived experience as a guide to my writing, even as it takes me into places difficult to understand.

Literature Review

This section reviews the literature on the biomedical perspective of Alzheimer's, and why the biomedical perspective is insufficient in gaining a thorough understanding of the lived experience of Alzheimer's disease. Different explanatory models of Alzheimer's disease affect not only the experience of those living with the disease, but also how we support people and their families through different therapeutic modalities, from pharmaceuticals to nursing homes to public funding for research to psychotherapy, right down to how we simply have conversations with people who have Alzheimer's. They also influence how we relate to our loved ones who have Alzheimer's disease.

I will review experience-near accounts of Alzheimer's disease that exist in the literature and examine what gaps there are in that body of knowledge. The purpose of this literature review is to demonstrate that an autoethnographic, critical phenomenological study on loving somebody with Alzheimer's disease can contribute important knowledge to various dimensions of the lives of people who have Alzheimer's disease and the people who love them, as well as to overarching understandings of being in the world during the time of the Anthropocene.

Biomedical Discourse on Alzheimer's Disease

In this section, I will review important literature on biomedical perspectives of Alzheimer's disease, pointing to limitations of this model and the effects of those limitations on people with Alzheimer's disease. Models of disease are theoretical models that are used as a kind of roadmap to diagnosis and treatment. They conceptualize disease and health based on a number of theoretical assumptions. In the last century, the biomedical model became the predominant model of Western medicine. An excellent working definition for the biomedical model of medicine comes from George Engle, who was the first to publish critiques of the biomedical

model and advocate for a less reductive approach to medicine. He wrote that the biomedical model of disease:

...Assumes disease to be fully accounted for by deviations from the norm of measurable biological (somatic) variables. It leaves no room within its framework for the social, psychological, and behavioral dimensions of illness. The biomedical model not only requires that disease be dealt with as an entity independent to social behavior, it also demands that behavioral aberrations be explained on the basis of disordered somatic (biochemical or neurophysiological) processes. (Engel, 1977, p. 130)

Engle wrote his critiques in the 1970s, and advocated instead for a biopsychosocial model of medicine, which incorporates social and psychological factors alongside physiological understandings and treatments of disease. The biopsychosocial model has gained acceptance as an improved model of disease in the decades since, however it has also gained criticism, particularly about the difficulty doctors have in actually applying such an integrated model of medicine (Farre & Rapley, 2017). As a result, what is practiced today in Western medicine may be more of a “split model,” in which the psychosocial factors of disease are used as an optional add-on to the still prioritized physiological factors (Herman, 2005). In my discussion of the biomedical model that proceeds from here, I will use the term biomedical to mean this “split model” approach, where the physiological explanations and treatments are the predominant way of understanding disease, with some psychosocial dimensions as secondary factors, as this typifies the current biomedical approach.

The biomedical perspective is not only dominant in fields where we might expect physiological considerations to be prioritized like oncology or gynecology. The fields of

psychology and psychiatry have also been profoundly impacted by this model over the last century. Even the former American Psychiatric Association (APA) president and current chair of the DSM steering committee, Paul Applebaum, noted in 2003 that, “our brains are biological organs by their very nature. Any [mental] disorder is in its essence a biological process.” (Deacon, 2013, p. 848). Brett Deacon explains that the “core tenets of this approach include: (a) mental disorders are caused by biological abnormalities principally located in the brain, (b) there is no meaningful distinction between mental diseases and physical diseases, and (c) biological treatment is emphasized” (2013, p. 847).

Alzheimer’s disease, a neurocognitive disorder, falls under the shared disciplines of psychology and neuroscience. Alzheimer’s disease is typically understood in biomedical discourse as a progressive and pathologically degenerative neurological disease that causes neurofibrillary tangles and b-amyloid plaques in the brain (D. H. Davis, 2004, p. 369). It has been hypothesized that the plaques and tangles cause the neurons to die, and thus create the progressive memory dysfunction, aphasia (difficulty speaking and understanding words), apraxia (difficulty performing skilled movements), hallucinations, and delusions typical of the disease (Sabat, 2018, p. 18). Although there is a correlation between the presence of plaques and tangles in the brain and Alzheimer’s Disease, no correlation has been found between the quantity of plaques and tangles found in a brain and the degree of cognitive impairment demonstrated in people with Alzheimer’s Disease (Sabat, 2018, p. 21). More recent biomedical research suggests that a loss of synapses is a better brain correlate of cognitive decline than the number of amyloid plaques or neurofibrillary tangles (Willén, Sroka, Takahashi, & Gouras, 2017). Additionally, new biomedical research suggests that the immune system is deeply involved in the etiology and progression of Alzheimer’s, alongside the nervous system. Heneka et al. claimed that “misfolded

and aggregated proteins bind to pattern recognition receptors on micro- and astroglia and trigger an innate immune response, characterized by the release of inflammatory mediators, which contribute to disease progression and severity” (Heneka et al., 2015, p. 2). The discovery of immune system involvement in pathogenesis has led to research showing that inflammatory factors such as diet, intoxicants such as alcohol, and exposure to certain toxic environmental chemicals are likely involved in the progression of the disease.

Although Alzheimer’s disease was virtually unknown to the public 40 years ago, it now attracts significant attention from scientific and public communities (Selkoe & Hardy, 2016). In 2006, the worldwide prevalence of people diagnosed with Alzheimer’s disease was 26.6 million people (Brookmeyer, Johnson, Ziegler-Graham, & Arrighi, 2007). It is estimated that by 2050, the prevalence will quadruple, resulting in 1 in 85 people worldwide living with the disease (Brookmeyer et al., 2007). This is primarily a result of increasing average lifespans globally, as age is the most significant risk factor correlated with the onset of Alzheimer’s disease. Indeed, the United Nations Population Division projects that the number of people at least 80 years of age will increase by a factor of about 3.7 by the year 2050 (Brookmeyer et al., 2007, p. 190). The scope of how many people worldwide are impacted by the disease has motivated biomedical interventions that can prevent or slow the progression of Alzheimer’s disease, as well as lay advocacy groups who emphasize the importance of non-curative care that will help better support people with Alzheimer’s disease and their caregivers to access a high quality of life.

The biomedical approach to treating the disease is focused on producing pharmacological and cognitive interventions that aim at preventing, reversing, or slowing the progression of the disease, particularly its impact on cognitive abilities. Secondly, it attempts to find ways of “managing” the challenging behavioral aspects of the disease, though who is primarily

benefitting from the management of symptoms—the person with Alzheimer’s or the people tasked with caring for them—is up for debate. The journal *Current Treatment Options in Psychiatry* recently published an article describing how the behavioral and psychological symptoms of dementia² “include a diverse group of psychological reactions, psychiatric symptoms, and behaviors that are unsafe, disruptive, and impair the care of individuals with dementia in a given environment” (Tampi, Tampi, & Balachandran, 2017, p. 56). Whose safety is at risk, and what metrics of safety are they implying? What exactly gets disrupted? What would un-impaired care look like, and who would it benefit? While biomedical perspectives attempt to generate biomedical interventions, such as pharmaceutical interventions that may prevent or delay the progression of Alzheimer’s disease, they offer a limited perspective on the lived experience of Alzheimer’s disease, and prioritize interventions that extend the lifespan, preserve cognitive functioning, and reduce the cost of services above quality-of-life concerns such as emotional and relational wellbeing. Operating from the foundational perspective of comparing disease state to the norm, there will always be an implicit favoring and superiority of the norm. Furthermore, these interventions are operating within a capitalist model of healthcare where profit is prioritized. The lack of attention to emotional and relational wellbeing is not an insignificant factor in the quality and duration of life for people living with Alzheimer’s disease. It is no accident that biomedical interventions prioritize curative treatments over ongoing care

² “Dementia” is a generic term referring to cognitive decline that impacts normal functioning, however it does not refer to a specific disease. The term is sometimes used as an umbrella term to describe numerous specific diseases defined by cognitive decline. Alzheimer’s disease is a specific neurological disease which accounts for the majority of dementia cases. The history of these words will be further explained below.

that focuses on enhancing quality of life.

Alois Alzheimer first described the disease in 1907 as an “unusual illness of the cerebral cortex” (Stelzmann, Norman Schnitzlein, & Reed Murtagh, 1995). While “senile dementia” was the term used at the time to describe a normal phenomenon of cognitive decline in older adults, Alois Alzheimer’s description of a previously unclassified disease was used to describe cognitive decline in individuals in their 40s or 50s, what we would now describe as early-onset Alzheimer’s disease. Doctors in the early 1900s “used the words *senile dementia* and *senility* interchangeably to describe mental deterioration in old age, physicians rarely distinguished between simple forgetfulness and its more malignant form” (Holstein, 2000, p. 162). Patrick Fox described how Alzheimer’s disease “emerged from an obscure, rarely applied medical diagnosis to its characterization as the fourth or fifth leading cause of death in the United States in little more than 12 years” (1989, p. 58). This began in the mid-1970s with the publication of Robert Katzman’s argument that “senile dementia” be recategorized as Alzheimer’s disease and included on the list of possible causes of death (1976). A major impact of this diagnostic shift in the 1970s was the pathologization of what was up to that point considered a normal part of aging.

Along with an increasing average life expectancy, this medical recategorization took place following a surge in cultural trust in biomedical interventions as the way to cope with medical and social issues, which was galvanized following World War II due to medical advances such as the polio vaccine. This confluence positioned a biomedical approach to treating Alzheimer’s disease as the most sought-after. As advocacy for research into the disease grew, so did the ‘small government’ ideology of the 1980s with the election of Ronald Reagan: the fiscal restraint of the time meant that “policy approaches promising a ‘cure’ were likely to prevail over those of ‘care’” (Chaufan, Hollister, Nazareno, & Fox, 2012). The outcome of these coinciding

social conditions was that a biomedical approach to defining and treating Alzheimer's disease became unquestioned, and the assumptions about selfhood underlying the biomedical approach to treatment seeped into the broader cultural discourse about how we understand the subjectivity of people living with Alzheimer's disease, contributing to narratives that equate loss of cognitive function with loss of selfhood.

The Issue of Selfhood

Biomedical discourses about Alzheimer's disease tend to utilize an implicit definition of the self that is based primarily upon identification with cognition and brain tissue. They foster a totalizing perspective; the person with Alzheimer's disease becomes the "Alzheimer-ed subject" (Hinton IV, 2011), their self-hood collapsed into disease-hood, indeed even into zombie-hood, a metaphor found in scholarly and popular literature about people with Alzheimer's disease, which describe them as the "living dead," "ghouls," and "animated corpses" (Behuniak, 2011). This dehumanizing and limiting outcome of the biomedical model of understanding Alzheimer's disease implores us to imagine how else we can take up the disease in a meaningful way, especially in a way that recognizes the preserved and enduring humanity of people living with the disease.

The "issue of selfhood" – that is, whether people with Alzheimer's have a "self" that persists throughout the disease, or whether it is precisely the "self" that dies slowly and perhaps completely before the person physically dies – is hotly contested in the literature (see for example: Davis, 2004; Kontos, 2012; Millet, 2011). Social scientists from social interactionist perspective have challenged the notion of the death of the self which precedes the death of the body in people with Alzheimer's, especially regarding how the self is constituted interpersonally. When a person's relational world interprets them in a totalizing fashion as the embodiment of a

disease, you see that “cultural definitions, care settings, and caregiving relationships [...] damage care recipients’ fragile self-esteem, leading ultimately to the loss of selfhood that is so widely thought to be caused by neuropathology alone” (Kontos, 2012, p. 2). From this perspective, the social field creates a significant loss of self, because of the unethical way in which people with Alzheimer’s disease are treated: as totalized beings who do not exceed the schema of Alzheimer’s.

Our “hypercognitive” culture tends to “exclude the deeply forgetful by reducing their moral status or by neglecting the emotional, relational, aesthetic, and spiritual aspects of well-being that are open to them, even in the advanced stage of the disease.” (Post, 1998, as quoted in Sabat, 2001, p. 320). This hypercognitive culture simply means that our society is one in which “the image of human fulfillment is framed by cognition and productivity” (Post, 2000, p. 34). This moral devaluation of people with Alzheimer’s disease based on their declining cognitive capacities is reinforced by the practices of clinical psychology and neuropsychology, which diagnose Alzheimer’s disease using tests which measure only a person’s cognitive capacities, categorically labelling the person with Alzheimer’s based solely on their cognitive deficits. There is no measure of so-called implicit memory, or of emotional memory in these tests. No measure of joy. No measure of resilience. The debate about selfhood in people with Alzheimer’s is slanted, and theories that people with Alzheimer’s have lost a “self” should be rejected because they fail to take into account the capacities which remain intact, as well as the new ways of being in the world which may include new strengths. Indeed, the idea that the “self” dies in people with Alzheimer’s before their body dies is based on a definition of selfhood that is based primarily upon activities of cognition. The consistency of the sense of self in time and place is something that can change in people with Alzheimer’s disease. For example, it is common for

people with Alzheimer's to think of themselves as existing in different moments in their life history, for example waking in the middle of the night to get ready to go to school. The inconsistency in locating oneself in a particular time and place creates a fluidity of subjectivity, which challenges our culture's notion that subjectivity is relatively static during each developmental period in a person's life.

Although it is undeniable that people with Alzheimer's disease continue to have a self, I agree with Daniel Davis that taken to the extreme, this insistence can signify an "unimpeachable personhood, which sanitizes the dying process." (2004, p. 377). This is to say, that there are real losses and changes in what constitutes the self over the course of the disease. Denying those changes and losses may unintentionally cause ambiguous and anticipatory grief of people with Alzheimer's disease and their loved ones to go unrecognized and unsupported.

Humanistic and Anthropological Perspectives of Alzheimer's Disease

While the biomedical discourse on Alzheimer's disease can richly describe some of the physiological phenomena, especially the progression of neurological change, it falls short in describing the lived experience of Alzheimer's disease, and inadvertently perpetuates dehumanizing discourses about the loss of self. Plaques and tangles do not explain the phenomena of how people actually continue to live their lives with Alzheimer's disease. Centering the lived experience of the person rather than the biomedical markers of the disease will answer different questions and provide different insights than the biomedical model can accommodate.

Fortunately, other perspectives of Alzheimer's disease have been written about over the last several decades, largely in response to the dehumanizing nature of biomedical discourses. Before Alzheimer's disease was delineated as a unique diagnosis, "senility" was the term used to

describe “the perception of deleterious behavioral change in someone understood to be old, with attention to both the biology and the institutional milieu in which such change is marked, measured, researched, and treated” (L. Cohen, 2006). Senility was depicted in the late nineteenth century as a state that threatened middle-class masculinity within an industrial age. Jessie Ballenger detailed how medical descriptions of senility near the turn of the twentieth century depicted stereotypes of the senile as “a miser, tyrant, fool, and dirty old man” (Ballenger, 2006). Ballenger noted that while the specificity of biomedical discourses on senility, and later the more specific designation of Alzheimer’s disease, has changed over time, the stigma of the disease has persisted as the behavior of people with Alzheimer’s continues to be depicted as “loathsome violations of propriety” to images of a “discredited self that was lost to the disease” (Ballenger, 2006, p. 115).

Tom Kitwood, a leading figure in person-centered, humanistic understandings of dementia, argued that dementia does not necessarily entail a radical disintegration of the person (1997). Kitwood posited that the experience of disease in dementia is not merely a neurological phenomenon, but that what happens neurologically in a person with dementia is always already intertwined with the person’s social environment. He described a “malignant social psychology” whereby the personhood of someone with dementia is undermined by their social context, particularly in caregiving environments where techniques of disempowerment, infantilization, intimidation, invalidation, accusation, and other dehumanizing behaviors are used to control the person with dementia (Kitwood, 1997). Kitwood characterized the “dialectics of dementia” as a spiraling interactive process, where neurological impairment and malignant social psychology interact, and malignant social psychology exasperates and possibly expedites neurological impairment.

Stephen Post explained the problems of a “hypercognitive culture,” which he described as the cause of our society’s tendency to “exclude the deeply forgetful by reducing their moral status or by neglecting the emotional, relational, aesthetic, and spiritual aspects of well-being that are open to them, even in the advanced stage of the disease” (1998, p. 72). That our culture has this attitude leads to “excess disability,” a concept that articulates the “discrepancy that exists when a person’s functional incapacity is greater than that warranted by the actual impairment” (Brody, Kleban, Lawton, & Silverman, 1971, p. 124). When a person with Alzheimer’s is treated in ways that reasonably can be expected to diminish their self-esteem, it can actually lead to further losses of ability (Sabat, 2001).

Pia Kontos (2006) described an embodied selfhood that persists throughout the progression of Alzheimer’s by drawing upon the philosophy of Maurice Merleau-Ponty and Pierre Bourdieu. She posited that the “presumed loss of selfhood is itself a product of the Western assumption that status as a full human being is completely dependent upon cognition and memory” (p. 195) and elaborated on the social model of Alzheimer’s disease as discussed by authors sampled above like Tom Kitwood, Stephen Post, and Steven Sabat. Kontos celebrated their humanistic contributions to our understandings of Alzheimer’s disease, but argued that “understandings about personhood and agency implicit in this revisioning derive from a presumed dichotomy between the body and the self” (2003, p. 159). The consequence, she argued, is that understandings of embodiment as a source of agency and selfhood have not been incorporated into the discourse on the subjective experience of Alzheimer’s disease, even by humanistic authors. Kontos instead suggested that the existential immediacy of the body as well as its interrelationship with culture and history describe a more accurate understanding of the enduring selfhood that persists through the progression of Alzheimer’s disease (2006). She

claimed that selfhood “emanates from the body as a generative spontaneity that asserts itself in an *improvised engagement with the world*” (2006, p. 214).

Alzheimer’s from a Phenomenological Perspective

Alzheimer’s disease can be understood phenomenologically as a disease marked by an enduring and multifaceted transformation in the lifeworld. Some argue that the disease is characterized phenomenologically by “a disintegrating cognition [and] impairment of the body schema [which] leads to an impoverishment of the lifeworld” (D. H. Davis, 2004, p. 375).

“Lifeworld” is a phenomenological term that describes how we actually experience and make meaning from living in the world in everyday situations and relations. Max van Manen foregrounded four different existential dimensions of the lifeworld that are fundamental to lived experience in general: “lived space (spatiality), lived body (corporeality), lived time (temporality) and lived human [and other-than-human] relation (relationality or communality)” (2016, p. 101). These dimensions of the lifeworld are understood as existential because they are aspects of the lived experience of all beings. Eva Simms described the lifeworld as the “field of being,” within which a coherent identity emerges:

The relative coherence of human identity has its foundation not in the outline of the skin but in the coherence of a lived body as it is chiasmically woven into the places, people, and things of its world. Selfhood is a field of being, a particular matrix of interpersonal and spatial relationships with the body at its center (2008, p. 24).

By foregrounding the lifeworld rather than a biomedical discourse as the starting point for investigating the phenomenon of Alzheimer’s disease, it is possible to avoid reducing a person to their physiological, and especially their neurological and cognitive dimensions.

Beginning with a phenomenological perspective opens up a series of new questions about

what the everyday lived experience of people with Alzheimer's might be like. Questions emerge such as: what happens to a person when Alzheimer's disease tugs loose the threads that weave her into the places, people and things of her lifeworld? And what happens to the places, people and things from which she becomes unwoven? How might memory function as the thread that actually weaves a person to her being-field? Do memories exist in the brain (as biomedical narratives assert), or might memories be phenomena that are more accurately described as being located in an embodied, cultural, relational field, beyond the periphery of the skin?

The Anthropocene

To understand the lifeworld means to understand lived experience within a specific situatedness in place and time. In this project, I will anchor this place and time in the frame of the Anthropocene. Although I locate my project in cultural phenomena that are situated within the United States, the context of the Anthropocene is an important one for my exploration of the lifeworld as I explore themes of being, forgetting, and dying within this time and place. The term "Anthropocene" literally means "the age of human," and describes "a geological epoch in which earth's atmosphere, lithosphere, and biosphere are shaped primarily by human forces" (Ellis, 2009). The term was first born in the field of geology, to indicate that "human activity is largely responsible for the exit from the Holocene [the previous geological epoch], that is, that humankind has become a global geological force in its own right" (Steffen, Grinevald, Crutzen, & McNeill, 2011, p. 843). I chose to situate this project in the context of the Anthropocene because it simultaneously captures the agent of change – human behaviors of exploitation, extraction, and consumption – and the systemic scope of the effects – all systems of the earth. Anthropocene describes a relational phenomenon between a *particular type* of human activity and place. While understanding the impacts on the planet is an important part of recognizing the

significance of the Anthropocene as a framework for understanding my project, what is more important is how the Anthropocene has made a particular kind of human life, a particular kind of subjectivity, the dominant mode, which has in turn made these deleterious effects on the planet possible.

This global geological force – humankind – is changing our planet’s climate at a profoundly rapid pace, with devastating consequences already apparent. The US National Academy of Sciences first warned of a warming climate due to human activities as a major threat to humankind in 1979 (Archer & Rahmstorf, 2010, p. viii), and scientific evidence has been mounting ever since about the multitude of ways that humans have fundamentally altered the earth beyond climate, including deforestation, desertification, urbanization, and mass extinction. Some scientists argue that the Industrial Revolution beginning in the 1700s marks the beginning of the Anthropocene, when human activities shifted from subsistence agricultural means of altering ecologies to capitalist markets of extraction that were propelled by the use of fossil fuels, completely transforming the ecology and sociopolitical landscape of England and beyond by 1850 (Steffen et al., 2011). Others argue that the beginning of settler colonization marks the start of the Anthropocene, with start dates ranging between 1492 and 1610, citing the importance of colonization as an engine for climate change (H. Davis & Todd, 2017, p. 766). This correlation connects the importance of decolonization as an intervention in slowing the climate chaos we see today. Importantly, these changes in human society were made by moving away from reciprocal economies toward extractive and exploitative economies, which required shifts in how people perceive the world and experience their existence (Kimmerer, 2013).

The 1950s to the present is known as “The Great Acceleration,” a period when the scope and impact of human enterprise increased exponentially. Between the 1950s and the early 2000s,

the global human population doubled from 3 to 6 billion, economic activity rose 15-fold, fossil fuel use increased by a factor of 3.5, and over half the global population migrated to urban areas, leaving behind agricultural lifestyles and adopting consumerist ones (Steffen et al., 2011). This period of acceleration caused massive shifts in all aspects of the environment, impacting atmosphere, watersheds, biodiversity, and so on. See Figure 1 on the next page for a visual representation of the dramatic changes to the environment and to human economies over the Industrial Revolution. Since the turn of the 21st century, trends of the great acceleration have continued and expanded, as the consumption of fossil fuels has extended beyond the Western countries that drove it in the 20th century to include nations like China, India, Brazil, South Africa and Indonesia (Steffen et al., 2011). Although scientific recognition of climate change and biodiversity loss resulting from global human society began in the 1960s, the rates of change and loss have only accelerated since that time, “initiating a mass extinction episode unparalleled for 65 million years,” meaning that “on human time scales, this loss would be effectively permanent because in the aftermath of past mass extinctions, the living world took hundreds of thousands to millions of years to rediversify” (Ceballos et al., 2015). The Anthropocene is a geological epoch of profound change and existential threat, whereby humans are rapidly destroying the ecologies that we are dependent upon for our own survival.

In this dissertation, I unfold ideas around a global society that has seemingly forgotten what the means of reproduction of life are, such that we are actively creating a future in which human life will not thrive, with some scientists (albeit a minority) even predicting the possibility of civilization collapse within my lifetime (Bendell, 2018). Further, my Mom was born in 1946, meaning her lifetime entirely coincided with the period of great acceleration described above. Our relationship has many inheritances of remembrance and forgetting during this transitional

time on earth, and I attempt to write into the forgetfulness of the Anthropocene by remembering my interwovenness with my Mom and our interwovenness with this time and place.

Figure 1

Figure 1. (a) The increasing rates of change in human activity since the beginning of the Industrial Revolution.

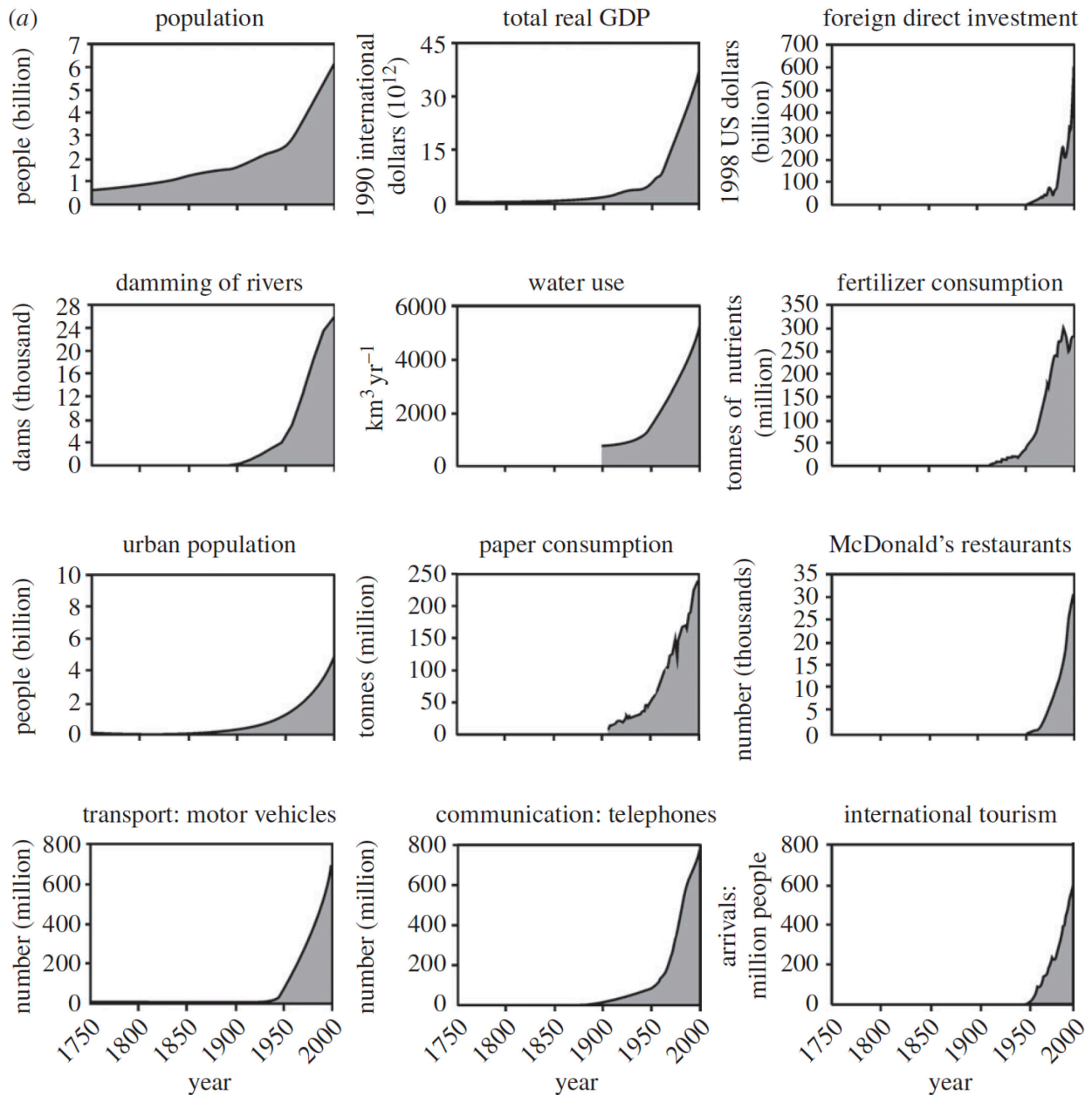
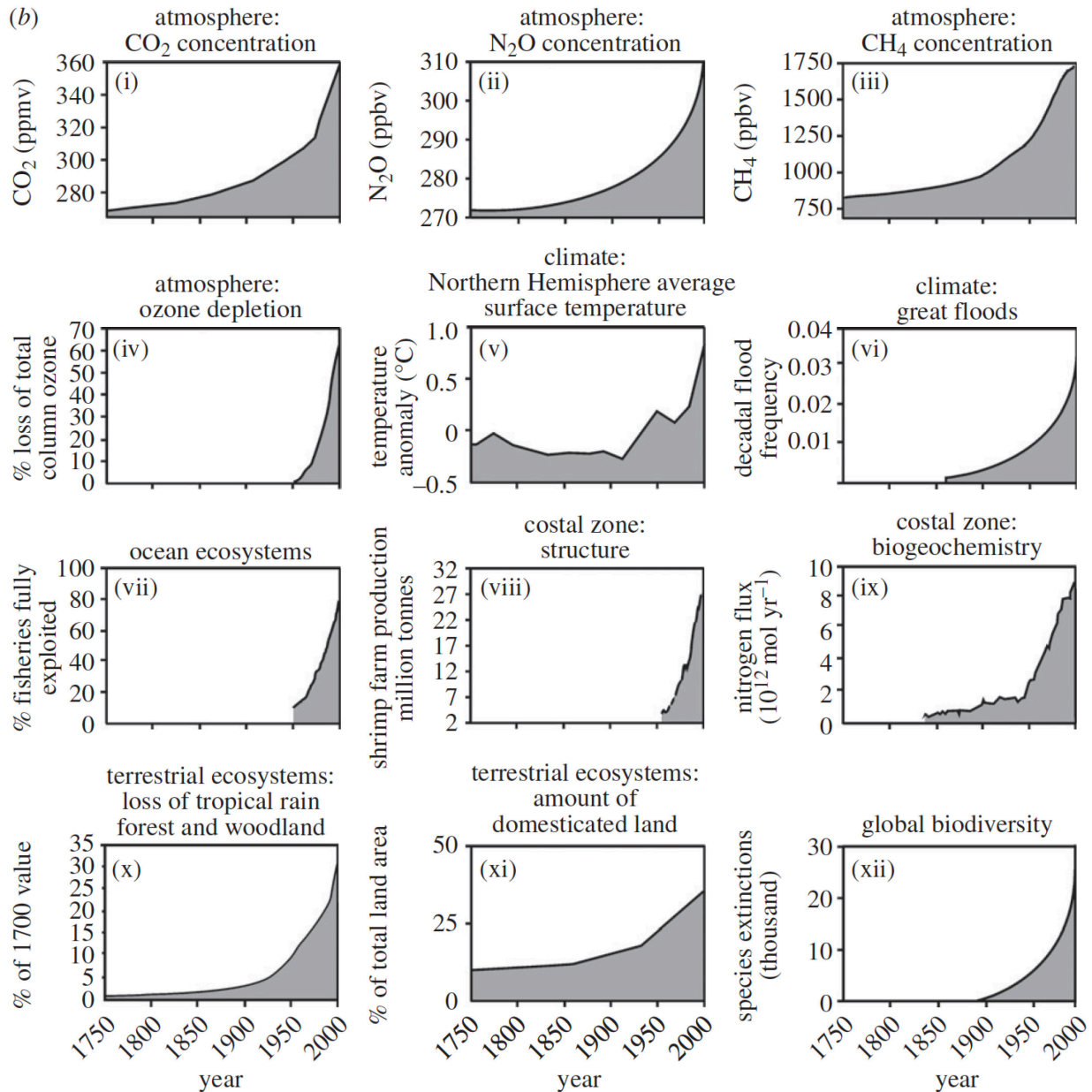


Figure 1, continued. (b) Changes to the Earth resulting from increase in human activity.



Note. Figure 1 from Steffen et al. (2011, pp. 851-852).

Methods

The goal of this project is to explore what it was like to share a relational world with my Mom while she lived with Alzheimer's disease and at the same time be deeply responsive to the sociopolitical and historical dynamics of living in the Anthropocene. I want my readers to feel in their bodies the rhythms of remembering, the textures of lifeworlds and temporal horizons shuffling. I want my readers to question what they have forgotten, to feel their own lacunas of belonging, and to inch toward the portals of liminality we are invited to enter by our forgetful elders. I also wanted this project to be a bridge that could keep me in connection with my Mom following her journey through living with Alzheimer's disease.

Given my personal connection to the subject, the umbrella method used in this dissertation is autoethnography. This method allowed me to explore the deeply interpersonal and emotional aspects of being in relation to my Mom while she had Alzheimer's disease, and to move through the research process in my own embodiment and with my own wounded heart as a critical piece of what can be known about the experience of loving somebody with Alzheimer's. Drawing from ethnographic roots and the "thick description" of cultural experience in meaningful context (Geertz, 1973), autoethnography opens up the investigation of embodied experience and addresses issues related to other ethnographic approaches of appropriation and exploitation of the Other as an appendage of colonial expansion. Using autoethnography allowed me to approach understanding the lived experience of being in relation to my Mom while she had Alzheimer's disease within a particular sociocultural context, and to simultaneously respect that I cannot know what my Mom, or others with Alzheimer's disease, are really experiencing. It allowed me to stay in my body and share what I know, which turns out to be a lot, while avoiding claims about my Mom's experience that I could not definitively know. The relational

field between myself and my Mom was, and continues to be, a rich and mysterious place for exploration. As Merleau-Ponty wrote with respect to being in relationship, “It is in the space between him and me that it unfolds” (Merleau-Ponty, 2004, p. 63), meaning that existence becomes meaningful only through our interactions with our lifeworld. I took this deeply to heart as I prioritized autoethnography as my method of choice and trusted that the relational field between my Mom and I was a place where a meaningful understanding of being, forgetting, and dying in the Anthropocene could be found. Adams and Holman Jones wrote that autoethnographies, like queer theory, “take up selves, beings, ‘I’s, even as they work against a stable sense of such self-subjects or experience and instead work to map how self-subjects are accomplished in interaction and act in and upon the world” (T. Adams & Holman Jones, 2008, p. 379).

Through the exploration of my relating to my Mom and of reading other accounts of living with Alzheimer’s, I attempted to examine how certain existential facets of life are altered through the experience of Alzheimer’s disease as well as by loving somebody who has Alzheimer’s. I looked at how my Mom and others with Alzheimer’s experience embodiment and dwelling in a place and time, how they relate to things, and how they relate to other beings, human and otherwise. Some of these descriptions were influenced by phenomenological methods of inquiry, most explicitly from the writings of Maurice Merleau-Ponty. I resisted adapting a structured incorporation of phenomenological methods of inquiry, however, as I wished to keep my mode of inquiring into this topic as open to improvisation and creative expression as possible. Therefore, I did not adapt the work of thinkers like Amedeo Giorgi (2009), who created a very structured form of doing phenomenological research.

I am asking what we can learn from people with Alzheimer’s disease about being,

forgetting, and dying in the sociopolitical global epoch we are in, which may be called by many names, which I will call the Anthropocene. I explore how a close observation of the lived experience of people with Alzheimer's disease exposes shortcomings in how we care for one another, due to structural issues such as colonialism and capitalism and their resulting stratifications of power and erosion of familial and communal support networks, as well as our alienation from place and our extractive relationship with the earth. I examine the apparently fluid subjectivity of people with Alzheimer's may offer us a new perspective on living and dying well in an era of deep, collective forgetfulness about our interconnectedness with human and non-human beings.

Autoethnography and Critical Bifocality

Autoethnography is most simply defined as a method of research that studies the self in relation to culture. It aims to use the researcher's "personal experience to describe and critique cultural beliefs, practices, and experiences" (T. E. Adams, Holman Jones, & Ellis, 2015, p. 1). It is a method that first began to be articulated in the 1970s, initially as a reparative move to ethnographic research, which was under scrutiny for its lack of reflexivity of the researcher. The problem that resulted from the lack of reflexivity was that ethnography was being used as a tool of colonialism, describing "the Other" without grasping the positioning of the researcher being implicitly positioned as superior, more civilized, and so on. Furthermore, ethnography was used as a political tool for colonial expansion. This is not a metaphor (Tuck & Yang, 2012): academic anthropology and the practice of ethnography was intentionally and explicitly used as an appendage of the state for "the construction of colonial and neo-colonial societies through ethnographic practice" (Pels & Salemink, 1994, p. 1). The emerging method of autoethnography was intended to invite researchers to investigate their own subjective experiences and their own

cultures, and to open up a critical reflection on their own positionality and culture, which tended to be obscured in ethnography. The method that took shape dialogues personal experience with cultural critique, revealing situated aspects of the relation of self to culture in ways that may reveal, question, resist, or transform normative cultural discourses in the researcher's home culture(s) (T. E. Adams et al., 2015).

Autoethnography is sometimes dismissed as a “navel-gazing” method that dwells in the personal to such a degree that it is not relatable or a source of valuable information (Sparkes, 2002). And indeed, there are examples of the method being used in such a way that is not sufficiently connected to a cultural investigation. It is true that autoethnography goes against dominant paradigms of research by prizing the subjective as an important form of knowledge. Against accusations that autoethnography is self-indulgent, Arthur Bochner and Carolyn Ellis (2016) argued that researchers are more susceptible to self-indulgence when they practice methods that allow them to believe that their subjectivity, including their social locations along race, gender, and class lines, can be prevented from “contaminating” their science.

One of the clear advantages to autoethnography is that it is evocative and embodied, recognizing “the embodied person as an epistemically fruitful condition for the production of knowledge” (Breuer & Roth, 2005, p. 426). Being able to write about your own embodied, affective experience of the self-culture relationship provides important information that is difficult to access in less embodied ways. These experiences can be written about in a way that evoke embodied learning on behalf of the reader as well. Not only is this a valuable form of information, but it is a form of knowledge that is in short supply in our current sociopolitical climate, and thus gives access to a type of knowledge that may be especially revealing about sociopolitical conditions. Jones & Harris wrote, “the political and scholarly potential of

autoethnography is still very much emerging and expanding, particularly in its potential to both evoke empathic and affective responses at a time of public numbness, a practice crucial to making scholarly research relevant to the work of global citizenship” (2019, p. 4).

Autoethnography is not another form of memoir, in that autoethnography explores and prioritizes the cultural dimension of personal experience, it engages with and extends existing research, and it makes a direct appeal to the embodied experience of the reader (S. Jones, Adams, & Ellis, 2016).

This overarching framework of moving between embodied, lived personal experience and sociopolitical context is captured well by the term “critical bifocality.” Critical bifocality is a term introduced by Michelle Fine and Lois Weis, who articulated it as: “a theory of method in which researchers try to make visible the sinewy linkages or circuits through which structural conditions are enacted in policy and reform institutions as well as the ways in which such conditions come to be woven into community relationships and metabolized by individuals” (2012, p. 174). Critical bifocality, although not confined to articulating personal experience and often used in ethnographies as well, aims to understand how structures of sociopolitical power get under our skin, and so there is a generative resonance between autoethnography and critical bifocality.

Why use autoethnography in my dissertation? Because as I aim to understand interdependence with people who have Alzheimer’s disease within this sociohistorical moment, I wanted to get as close with all my senses as I could. One of the significant challenges with this work is that as the disease progresses, people with Alzheimer’s tend to lose their ability to speak. The world of words gets loose and different forms of communication are needed, which move from the body. How do I ask with traditional methods of inquiry about what it is like to *be* with

Alzheimer's? Traditional methods such as interviews are helpful with people in the early stages of the disease, but are simply not practical or possibly even ethical in the later stages. This conundrum is played out in scientific research, as there are far fewer studies that examine the lived experience in the moderate or severe stages of the disease than there are in the mild earlier stages.

Prizing this ethical conundrum, I decided to ask myself instead: how am *I* in relation to my Mom? Understanding that I would only get a partial perspective of her experience this way, I wanted to make a case for the particular positioning I have had in relation to her that gives access to the intersubjective realm of experience. My body began from her body, and my spirit from hers. She trained my senses in my childhood and I am fluent in the language of her touch, gestures, facial expressions, all of which she continued to communicate through up until her death. Without the rhythm of relating between self and other, there is no self: “there is no ‘inner’ life that is not a first attempt to relate to another person” (Merleau-Ponty, 2004, p. 67). Both my Mom and I have become who we are together, through one another, amongst our many other relationships. Autoethnography allowed me to document my observations from a deeply felt sense of my own experience of being in relation to her. It gave me a chance to express the language of relating to her that I know in my bones. It is a method which allowed me to do research in a home of relational ethics. It allowed me to be flexible and creative, and gave me authority to share what I have learned from my Mom about our journey through her experience of Alzheimer's disease.

Phenomenological Inquiry

My dissertation is informed by phenomenological inquiry, which I used like a tool within the overall toolbox of autoethnography. My recollections about my Mom informed the

phenomenological investigation I explored by examining how the core existential facets of life are altered through the experience of Alzheimer's: how she experiences embodiment and dwelling in a place and time, how she relates to things, and how she relates to other beings, human and otherwise.

Phenomenology offers a way into lived experience through the lifeworld, the world as we live it, pre-reflectively rather than conceptually. It allows for the “study of lived or existential meanings; it attempts to describe and interpret these meanings to a certain degree of depth and richness” (Van Manen, 2016, p. 11). I am attracted to the way that phenomenology understands existence, that it researches what it means to be human, to be attuned to others and to the world around us, to see the hidden under the apparent. Phenomenology sees that “the ‘external’ world, body and consciousness are all fundamentally intertwined, inter-relating and mutually influencing” (Allen-Collinson, 2011, p. 3). It is an exceptionally useful methodological attitude to use to describe relationality. I resonate with Allen-Collinson's description of the gift of the phenomenological attitude, which she describes as “one of enchantment, an attempt to suspend our ‘adult’ knowledge and preconceptions in order to view the world through the fresh, excited, ‘naive’ eyes of childhood” (Allen-Collinson, 2011, p. 5). This especially resonates with my project, where my embodied memories of being with my Mom were the playground of experience that I drew from for my analyses.

If the psychological dimension of human life cannot be captured by quantitative forms of analysis, Maurice Merleau-Ponty asks in *The World of Perception*, what else can we know about it, and how? He invited psychological inquiry to depart from Cartesian dualism, pointing instead toward a cohesive world of meaning accessible through perception, which cannot be known by a “utilitarian attitude” of disembodied intellect (Merleau-Ponty, 2004, p. 31). The world of

perception is accessible through bodily engagement in the sensorial world within which one dwells; it welcomes those who approach with a playful and embodied method of understanding. Indeed, “we live meanings through bodily participation in the world” (Todres, 2007, p. 33), and so I attended to topics like how people with Alzheimer’s move through the world, and how the people in their lives move around and with them.

Bracketing is an especially helpful practice that I borrowed from phenomenology. Alzheimer’s disease has a sedimented discourse around it as a biomedical, neurological disorder. As our culture has become increasingly obsessed with understanding the brain as the central locus of who we are and how we experience the world, Alzheimer’s and other neurocognitive disorders have been associated with the loss of self, the loss of identity, death in life (Behuniak, 2011). Van Manen described bracketing as a way to “come to terms with our assumptions, not in order to forget them again, but rather to hold them deliberately at bay and even to turn this knowledge against itself, as it were, thereby exposing its shallow and concealing character” (2016, p. 47). It was therefore a helpful practice to lift off this sedimented discourse around Alzheimer’s disease and get curious about what it may be like to live with it, both being embedded in such discourses and on a more embodied, pre-verbal level of experience.

Cultural Criticism

An important part of my dissertation was to eventually flip the question on its head and ask: what can we learn from our most forgetful elders about what it means to remember, to be, and die in the Anthropocene? We, who have forgotten so much about being in relationship with each other and with the broader ecology of non-human beings with whom we live and upon whom we depend for our survival. To ask this question means I already have a critique, clearly, of our culture. I aimed to understand through the experience of people living with Alzheimer’s about

what is going wrong with our society, and what we might be able to learn about how we can improve it from people living with Alzheimer's.

The cultural critique part of the dissertation is the least connected with a particular method, but it falls under the umbrella of autoethnography nonetheless, as it examines the culture we are situated in. I drew inspiration here from Indigenous and other thinkers who contemplate colonialism, socialist feminist thinkers, and ecopsychologists, among others, to make sense of our sociopolitical context. My aim was to look closely at the sociocultural context within which people in the United States (and to some extent the broader globalized Western world) have Alzheimer's. To get descriptive about the structures that get under our skin. Again, this picks up the critical bifocality discussed above, and this time centers the context, and positions people with Alzheimer's as the ones who may have something important to teach the rest of us.

A Twist in the Project with my Mother's Death

My Mom died in April of 2019. While I began this dissertation as a project for me to learn how to stay in connection with her through all the changes she was going through, the task, in some ways, changed after her death. When I began this project, I planned to incorporate more "live" observation, using data collection practices such as field notes. Following her death, I transitioned the project somewhat to be focused instead on data collection from my own memories. Van Manen wrote, "sometimes the best anecdotes are *re*-collected as one tries to make sense of things that somehow seem interesting now, in hindsight" (Van Manen, 2016, p. 69, italics in the original). This project saw me through the beginning of hindsight, as she died after it began.

While my relationship with my Mom is ongoing, since she died my experience of being with her has changed dramatically. I now find it easier to recall memories from when she was

healthy. In the few months immediately following her death, I experienced memories of her more vivid than any I've ever had before, as I will detail in the chapter "Time Traveling." Memories that felt real, as if what I was remembering was actually happening in the present. Perhaps this dissertation would have had different findings if she were still alive throughout the project. The timing of her death is, regardless, simply an important part of the introduction to this work, as it influenced not only my data collection methods but also surely my resulting data and analysis.

Data collection

The primary data collection for this dissertation is a series of written recollections presented as vignettes about my experience of being with my Mom while she had Alzheimer's disease. I also collected other sources of data such as artifacts and previously written observations to supplement my written recollections. I analyzed those data using phenomenological and critical cultural and psychological interpretations in subsections following each vignette. I collected personal memory data (Chang, 2008), that is, a series of recollections I have about interacting with my Mom throughout my lifetime, primarily focused on our relationship during the time she had Alzheimer's disease. I focused on emotionally resonant memories, so as to mirror one of my observations about her: that emotional resonance is a compass. In choosing these recollections, I aimed to stay primarily with my embodied, lived experience, and to write evocatively, so as to inspire resonance in my readers. The vignettes were selected to prevent redundancy in my analyses and to contribute to a coherent gestalt.

After writing several recollection vignettes, the next step in my process was to analyze each vignette, some of them through an existential phenomenological lens, and some through a

cultural criticism lens depending on what seems to be implicitly suggestive in the vignette. This structure of first crafting a number of stories and then allowing a theoretical interpretation emerge from the stories themselves is inspired by the dissertation of Dorothy Cashore (2019), who wrote an ecopsychological autoethnography using a similar structure. Part of what attracts me to the method with which Cashore wrote her dissertation is that the series of stories can be read independently of the theory and cultural criticism that emerges in the following analyses, making the text more experience-near and potentially accessible to a wider audience.

Summary

Studying the lived experience of Alzheimer's disease within the sociopolitical context of Western neoliberal colonialism and the Anthropocene can contribute to the working knowledge we use to make decisions about caring for people with Alzheimer's, as well as open questions to what we might learn from our forgetful elders in a sociopolitical context that requires a forgetting of interdependence in order to be reproduced. This dissertation aims not only to further progress the lineage of humanistic and phenomenological-anthropological understandings of Alzheimer's disease, a body of work which primarily serves to critique, correct and repair the problems of biomedical discourses on Alzheimer's disease and other dementias. This dissertation aims to step beyond the position of reparative reading of people with Alzheimer's, to establish a generative reading of what we might learn from the wisdom of our elders with Alzheimer's disease about being, forgetting, and dying in the Anthropocene.

Chapter 2: The Elephant in the Room

One of the most tender parts of my experience in being with my Mom while she had Alzheimer's Disease is that she never spoke with me about that fact that she had it. Not once over the four years that she was diagnosed with Alzheimer's. Not in the year before that when she had a diagnosis of Mild Cognitive Impairment. Or in the five years before that, when her "chemo brain" made everyone in my family spend time in private with their fears that she may be developing Alzheimer's. A decade altogether that Alzheimer's loomed over my family, shrouded in secrecy and denial. Writing that sentence makes my chest feel like there are steel plates weighing down on it. I sigh.

I recall the closest I ever got to discussing her diagnosis directly with her. My parents were still living in Portland, Oregon at the time, and I must have been around 26 years old. It was a warm, sunny summer day, and I was sitting in their backyard reading. Spending time at my parents' house after I graduated from college always made me feel like I was back in high school again. I lived in Seattle at the time and would often spend a few nights with them when I came to visit, to make the 3-hour drive worth it. Sleeping in my old twin bed, all my belongings from high school still decorating my bedroom, posters from movies I used to like still hanging on the walls, it was like a time capsule in my bedroom from when I was 18 years old. It was easy for me to revert back to feeling like a teenager: misunderstood, easily annoyed, defensive.

On this visit, my parents happened to have an appointment with my Mom's neurologist, who had diagnosed her with Mild Cognitive Impairment and had insisted that she not be allowed to drive anymore. This was a major blow to my Mom's sense of independence, and she was incredulous. She came outside to see what I was doing, and her rage followed her, red under her skin, sharp and acrid in her voice. When I asked what was wrong, she told me that the doctors

were lying and trying to take her driver's license away, and that she was just fine. She was furious with my Dad and suspected that he was the mastermind who had found these doctors willing to lie and take away her independence. The air around her seemed to turn red and electric with her anger.

Moments like these pose a question to loved ones. Do you join with her? Argue another perspective? Distract and deflect? Being her daughter in this situation brought all of these questions into the framework of our relationship and throttled us by spatial association into the time period when I was in high school. That meant that disagreeing would make me the stubborn child. Redirecting would make me patronizing. Joining with would make me collude with something seemingly dangerous and would increase the emotional labor for my Dad if I blew wind in the sails of her demand to keep her driver's license. The small child in me, whose relationship to her mother was simple, loving, and utterly dependent, was terrified that my Mom was saying something with such raw emotion that I simply did not understand: what does she mean, my Dad is the mastermind?

Years later, it is easier to analyze these options of how I might have responded. Now that I've had several years of engaging with my Mom while she had Alzheimer's disease in the time since this story took place, I have learned many lessons about what worked and what didn't when trying to connect with her. Training to become a clinical psychologist in the later years of her illness also helped me learn communication strategies like reflection and resonance. But at the time, this was still new for me, and what to do was not so clear. When it happened, I felt confused and put on the spot, but hungry for the slight acknowledgement—even acknowledgement by explicit denial—that Alzheimer's was in the picture at all.

I did what I could to try to receive her anger and calm her down, but I'll readily admit I didn't do a great job. I felt so emotionally torn, and at first I tried to avoid the conversation entirely by offering her a glass of water, hoping that it would redirect her. That only made her angrier, and understandably so – I was not offering any resonance to her devastating anger about losing her driver's license. It is hard for me to remember what happened after that – the powerful, flashbulb part of this memory was the startle I felt by her partial acknowledgement and anger. What I do remember is that I tried to side with her neurologist, asking why a doctor would lie to her. Looking back, I imagine it was hurtful to my Mom for me to “stick to the facts.” But something about deviating from them felt scary, like I may just be stoking the flames of her anger. And more than anything, I wanted to connect with her about the most difficult thing that has ever happened to me: my Mom having Alzheimer's. I was desperate for her to meet me in that fact, so I did everything I could to try to make her join me there. It was to no avail.

Denial

Denial is a common experience of people with Alzheimer's disease, especially in the early stages. Denial is “an instant, nonreflective process,” which is different from the more conscious process of repression; denial says “This is not happening,” while repression says “This happened, but I'll forget about it because it's too painful” (McWilliams, 2011, p. 103). Another way to understand denial is as a process of “avoiding awareness of aspects of external reality that are difficult to face by disregarding sensory data” (Gabbard, 2014, p. 37). By disregarding sensory data, denial can be understood to happen unconsciously, that is, before any conscious arrangement or interpretation of sensory information has happened. Although denial is understood as a “less sophisticated” defense mechanism than altruism or humor (Gabbard, 2014),

it is commonly experienced by people in both benign and more troubling situations throughout the lifespan. For example, denial is common in emergency situations where denying the intense emotional response of a life-threatening situation can make the difference between life and death, such as denying overwhelming fear in order to run toward a fire to rescue someone. However, denial can also lead to life-threatening situations, such as when people misuse psychoactive substances and deny they have a problem to such a degree that they become seriously ill or even die.

Imagine that you are in the 7th decade of your life, and you notice you are starting to forget things that once came easy to you: the name of your friend's wife, the route home from across town. After putting it off for some time, you make an appointment with a neurologist after a scary incident of getting lost and not remembering where you live. After a series of tests, possibly a PET scan, your doctor gives you the news: you have probable Major Neurocognitive Disorder due to Alzheimer's Disease. A fatal disease. Although Alzheimer's disease looms in our cultural consciousness as a well-known illness among older adults, what the general public thinks about is the forgetfulness, not the deadliness. Being diagnosed with a terminal illness that causes the steady decline of short- and long-term memory faculties, as well as the loss of speech, motor skills, and the ability to live independently is, understandably, devastating to most people. When the degree of loss is considered, psychological defenses like denial make perfect sense.

In the history of the field of psychology through the 20th and beginning of the 21st centuries, there has generally been a movement from predominantly psychoanalytic descriptions of psychological phenomena in the era of Sigmund Freud, to other epistemologies, first with behavioral explanations, then social explanations, and finally neurological explanations coming to dominate the field by the 1990s. As technologies allowed for more detailed mappings of the

brain, both research and cultural discourses at large about why we experience the world the way we do began to favor neurological explanations, boiling down to the explanation that a series of neurons firing creates your lived experience. It was perhaps an over-correction of the psychoanalytic heyday in which experience was explained through unconscious drives. It is not a coincidence that neurological descriptions also neutralized “blame” away from the person, as well as away from environmental and political factors. By locating psychological phenomena primarily in the brain, neither personal nor sociopolitical change was actually required; rather these phenomena could be “managed” through the use of psychopharmaceuticals, a multi-billion-dollar industry. By the 2010s, a more concerted movement to integrate these various explanations started to spread through the field, and a biopsychosocial approach has recently become the aspirational norm, although in practice there remains an emphasis on neurological factors.

A biopsychosocial description of the phenomenon of denial in people with Alzheimer’s disease is a complicated endeavor, one that I will briefly outline here. When attending to the biological phenomena in the experience of denial in people with Alzheimer’s disease, the most relevant concept is “anosognosia,” which describes a “lack of awareness about illness or impairment” that correlates with brain lesions and neurodegenerative diseases (Mograbi, Brown, & Morris, 2009, p. 989). Anosognosia essentially describes the faulty neurological functioning of the ability to internally monitor one’s cognitive and behavioral functioning. Anosognosia is “not an ‘all or none’ phenomenon and it can vary in degree, from a lack of concern and attention to a neurological deficit to explicit verbal denial” (Morris & Hannesdottir, 2004, p. 275). Anosognosia includes multiple aspects of unawareness. Importantly, it traces the origin of the phenomenon to brain lesions, despite the fact that researchers have been unable to find a

relationship between degree of awareness deficits and generalized cognitive impairment, based upon measures of global cognitive functioning, memory, attention and language. (Burgess, Alderman, Evans, Emslie, & Wilson, 1998). It is no surprise that explanations of human behavior that focus on brain activity include exactly the kind of denial that I wish to unpack in this chapter. There is a denial that the biological theory is incomplete despite clear limitations of this perspective.

From a psychological perspective, Glen Gabbard describes denial as a way that people with Alzheimer's "defend against catastrophic anxiety by avoiding awareness of their defects" (2014, p. 388). Integrating the new information about having Alzheimer's disease requires also integrating that you may forget your loved ones; that you may forget important aspects of who you are; and that, more than ever before in your life, you are approaching death. Denial in this sense is an adaptive coping response to mitigate the catastrophic emotional impact that this information can have. Denial allows for a certain experience of life as open-ended and unimpaired to continue. It allows for the (more or less) seamless continuity of a lifeworld.

Lisa Snyder, a clinical social worker who has dedicated her career to better understanding the subjective experience of people living with Alzheimer's disease, compiled a series of interviews of people describing their lived experience of Alzheimer's. One person she interviewed, whose pseudonym is Bill, described his experience of being diagnosed with Alzheimer's:

At age 54, it seemed like I was labeled incompetent after a lifetime of proficiency. The psychologist who tested me said that I would find it increasingly arduous to work, or even drive a car. I was devastated. After the diagnosis, I remember walking out of the

clinic and into a fresh San Diego night feeling like a very hopeless and broken man. [...]

I wondered if there was anything for me to live for. (Snyder, 2009, p. 41)

Although Bill does not describe denial in part of his first reaction to being diagnosed with Alzheimer's, his wrenching description makes clear what is at stake, and why someone may grapple to integrate this information into their lifeworld, and how it could trigger a feeling of catastrophic anxiety. The diagnosis is threatening to his identity as a person who has always been proficient.

In addition to this classic understanding of denial, there's an additional psychological component to why denial may be called upon by people with Alzheimer's that is specific to the common feature of the disease of decreasing and ultimately ceasing ability to learn or remember new information, as well as the phenomenon that short-term memory tends to decline earlier and more thoroughly than long-term memory. "Because recent memory tends to be sacrificed before remote memory, many patients can clearly recollect how they used to be, which makes their current dysfunctional state all the more disturbing to them" (Gabbard, 2014, p. 389). The more disturbing the new information about oneself is, the more likely a person is to draw upon blunt defensive coping strategies like denial.

How is denial a social phenomenon? "Denial masks shame" (Wilson, 2003, p. 286). Or, in other words, denial is a strategy that is unconsciously employed to avoid the feeling of shame. Because the experience of shame can be so painful, it is common for the shame to "go underground" and be the agent of other defense mechanisms including denial (Scheff, 2004, p. 231). Denial is an escape hatch from the uncomfortable feeling of shame, and the relational consequences of disconnection, which also can decrease one's felt sense of safety and belonging. Shame is defined in Relational Cultural Theory, as "a felt sense of being unworthy of

connection” (Hartling, Rosen, Walker, & Jordan, 2000, p. 3). Shame exists in “an interpersonal context that is inextricably tied to relationships and connection [and to] the real or perceived failure of meeting cultural expectations” (Brown, 2006, p. 45). Denial from this perspective is a relational strategy that aims to maintain cohesion of identity and relational connections within a particular lifeworld by covering over a threatening truth. Returning to Bill’s testimony from above, his statement that he was “labeled incompetent after a lifetime of proficiency” (Snyder, 2009, p. 41) is exactly the kind of threatening truth that could generate a feeling that one is unworthy of belonging, if they identify their self-worth strongly with being proficient, as many Americans do.

Additionally, there are cultural influences on denial in the context of someone with Alzheimer’s disease. The scope of this study is focused primarily on the culture in the United States, however there are some similarities that extend beyond the US due to globalization and neoliberal imperialism. Of major import here is that the US has a culture of death denial perhaps unparalleled in the rest of human history. Over the last 100 to 150 years as death care became outsourced to hospitals and other businesses, the average lifespan extended, infant mortality rate decreased, and urbanization drove people to be disconnected from the animal death involved in their subsistence, people simply became less exposed to death. Knowledge about caring for people who are dying as well as how to tend to their bodies after death was lost as this outsourcing began. The impact of a culture of death denial in many ways returns to the phenomena of shame and fear: shame for being cast an outsider due to being terminally ill, and fear about experiencing death, a fear which is exaggerated because there is more about dying that is left to imagination and that is valued negatively.

Death became hidden, covered over, denied. In this sense, the cultural influence on denial in people with Alzheimer's disease is the same as any person facing a terminal illness. Add onto that a cultural understanding in the last 100 years in the US shifting ever more toward human subjectivity as defined primarily by cognition, no doubt influenced by the increasing economy of information. People with Alzheimer's disease are facing both their own death and the decline of that part of them that is most valued in our culture: their cognition. Falling out of belonging to a culture with which a person once felt strongly identified can easily lead to the feelings of incoherence that can trigger a response of denial.

Although denial is only rarely addressed in psychological research as an intersubjective or relational phenomenon, it is possible that the social aspects of denial may be the most powerful. Interpersonal and intersubjective theories of psychology and psychotherapy, such as Relational Cultural Theory (Jordan, 2018), illuminate the incredible importance of the social world on our psychological experience. The question that this brings up, is where exactly does denial exist? Is denial an internal psychological device? Or does it exist in the space between two or more people? Is it socially co-constructed? Eva Simms wrote, "The relative coherence of human identity has its foundation not in the outline of the skin but in the coherence of a lived body as it is chiasmically woven into the places, people, and things of its world. Selfhood is a field of being, a particular matrix of interpersonal and spatial relationships with the body at its center" (Simms, 2008, p. 24). Denial is a device that aims to maintain the relative coherence of human identity against threats of incoherence, and it is co-created by the places, people and things within someone's field of being.

Next, I will flip the question around from how denial shows up in people with Alzheimer's, to how denial shows up in American culture. I intend both to demonstrate that

people with Alzheimer's are not the "other," and that we may have a great deal to learn about being, forgetting and dying in the Anthropocene from people with Alzheimer's.

Denial in the Culture

The preceding subsection explored denial in an individual person. Denial is not only an intrapsychic phenomenon; it exists relationally, culturally, and institutionally as well. Stanley Cohen (2013, p.1) wrote:

One common thread runs through the many different stories of denial: people, organizations, governments or whole societies are presented with information that is too disturbing, threatening or anomalous to be fully absorbed or openly acknowledged. The information is therefore somehow repressed, disavowed, pushed aside or reinterpreted. Or else the information "registers" well enough, but its implications — cognitive, emotional or moral — are evaded, neutralized or rationalized away.

Denial is baked into the foundation of American culture. If we consider our foundation to be in part determined by the artifact of the declaration of independence, especially the phrase "life, liberty, and the pursuit of happiness," we can examine what kinds of roots it may hold of our collective denial. An aspirational phrase, "life, liberty and the pursuit of happiness" delineates good from bad: we want life, liberty, and the pursuit of happiness, and we don't want death, bondage or suffering. This aspiration, however, was intended only for white, land-owning men. The occurrence of denial here is twofold: it is the refusal of granting these ideals for anyone who was not in this category of people, and at the same time, a covering up of that fact by using universalizing language. Denial has a way of covering its own tracks; denying that denial has happened.

Although there are myriad artifacts of United States culture that could demonstrate our flair for denial, this phrase captures something important. The way we have taken up this phrase as a central motto to explain who we are and what our values are as a nation casts light on some of our shadows. It is not a coincidence that evidence of this phrase's opposite—death, bondage, and suffering—is kept hidden, if not outright denied in our culture. Indeed, our use of death, bondage, and suffering as tools to colonize Indigenous peoples and enslave Africans made the founding of the United States possible. Martin Luther King, Jr. wrote, “Our nation was born in genocide... We are perhaps the only nation which tried as a matter of national policy to wipe out its Indigenous population” (2000, p. 110). This fact is mostly denied, forgotten about, or painted over with a rosy hue. Historian Wai-Chee Dimock quotes from nonfiction sources in the time of Andrew Jackson's presidency: “whereas European powers ‘conquer only to enslave,’ America, being ‘a free nation,’ ‘conquers only to bestow freedom.’ ... Far from being antagonistic, ‘empire’ and ‘liberty’ are instrumentally conjoined.” (Dimock, 1989, p. 9). Denial in the national consciousness of the US functions as an important psychological device that turns genocide into a means of liberation, “reconciling empire and liberty—based on the violent taking of Indigenous lands—into a usable myth allowed for the emergence of an enduring populist imperialism.” (Dunbar-Ortiz, 2014, p. 106).

Sociologist Eviatar Zerubavel wrote, “the past is also part of a social reality that, while far from being absolutely objective, nonetheless transcends our subjectivity and is commonly shared by others as well” (1996, p. 283). The social reality, particularly established and maintained by the ruling class of the United States through educational, political, and media programs, uses denial strategically. “The study of national history is a major part of the general effort of the modern state to foster a national identity.” (Zerubavel, 1996, pp. 290-291). For

example, in late 2020 as I drafted this dissertation, an article was published in the Washington Post describing former President Trump's plans to modify standards of how history is taught in public schools in the US: "Trump said he would create a national commission to promote a 'pro-American curriculum that celebrates the truth about our nation's great history,' which he said would encourage educators to teach students about the 'miracle of American history,' [...] casting any criticism of the United States, even of slavery, as unpatriotic" (Balingit & Meckler, 2020). Here, acknowledgement of any inhumane practices on behalf of the United States Government would be seen as unpatriotic even in a classroom setting. Denial of particular histories is often used as a strategy to advance particular ideologies.

Cohen identified that "each variant of denial appears in the official discourse: *literal* (nothing happened); *interpretive* (what happened is really something else) and *implicatory* (what happened is justified). [...] The contradictory elements form a deep structure: their relationship to each other is ideological, rather than logical" (S. Cohen, 2013, p. 103). In the above example, Trump *literally* denied that the US was founded through the labor of slavery, calling it instead "a miracle," while simultaneously *interpreting* the fact of slavery as justified and *implying* that it would therefore be unpatriotic to criticize slavery. The three forms of denial are delivered together, supporting an ideology of nationalism. This strategy of denial linked with ideology makes it so that those who acknowledge the fact of slavery and the moral implication of our country having done harm via the institution of slavery, become cast as outsiders and even as enemies to the identity of being an American.

Denial here is used as a mechanism to define the borders of national identity. Denial aims to maintain coherence of an identity, even a national identity, by eliminating information that puts any part of that identity into question. "Remembering, after all, is more than just a

spontaneous personal act. It is also regulated by unmistakably social rules of remembrance that tell us quite specifically what we should remember and what we can or must forget” (Zerubavel, 1996, p. 286). American denialism is particularly invested in the denial of accountability for causing harm, which prevents any meaningful reparations or changes in behavior from occurring. Eviatar Zerubavel wrote, “society delineates the scope of our attention and concern, it also delimits our mental reach into the past by setting certain historical horizons beyond which past events are basically regarded as irrelevant and, as such, often forgotten altogether” (1996, p. 286). This is maintained in the United States through legal and economic structures, in which “individual responsibility could be masked in corporate personality... a legal abstraction” (Miner, 1976, p. xi.). The structure of public roles, such as a professional or a political title, acts as a shield from personal accountability, bolstering outright denial through limitations of responsibility protected by the division between one’s professional and personal personas. This, importantly, is what Hannah Arendt (1963) described as the “banality of evil” that allowed the atrocities of the holocaust to take place: because people followed the orders of their job duties they could deny personal responsibility.

There is a crucial parallel between the phenomenology of denial in people with Alzheimer’s disease and the phenomenology of cultural denial. When denial says, “That did not happen,” it re-writes our shared memory of a time and a place, re-configuring it. Part of what is painful about loving somebody who has Alzheimer’s disease is what happens when your own mental rendition of reality does not map onto theirs in the same way that it used to. In the story that precedes this section, I described how painful it was to not exist in a shared reality with my Mom about the devastating fact that she had been diagnosed with Alzheimer’s disease. That experience happened within the social context of a society that is profoundly individualistic,

which in this example had the effect of minimizing or overlooking how dysregulating and upsetting it feels to not have a shared sense of reality with others, particularly parents and other early attachment figures. Therein lies the fallout of denial: a severing of connection.

We form attachments not only with our caregivers, lovers and children, but also with our cultures, the histories we inherit, the land we live on, the air we breathe, the water we drink. Life is public and intimate everywhere. Denial aims to protect an internal coherence of any identity – be it personal, familial, or cultural – by rupturing connection with any person or fact that represents something that could be threatening to that internal coherence. Because we are deeply intersubjectively organized, when someone or something we have attachments to claims a different version of reality than the one we think we are in, we have a choice: maintain the attachment and leave our understanding of reality, or sever (or at least create a boundary in) the attachment and preserve our own understanding of reality. In the case with my Mom, at times I joined her in her lived lifeworld when she was living with Alzheimer’s, I left my own understanding of reality (which I will discuss in the “Timeless Time and Moving Spirits” chapter), an experience that was both painful and, at times, rewarding.

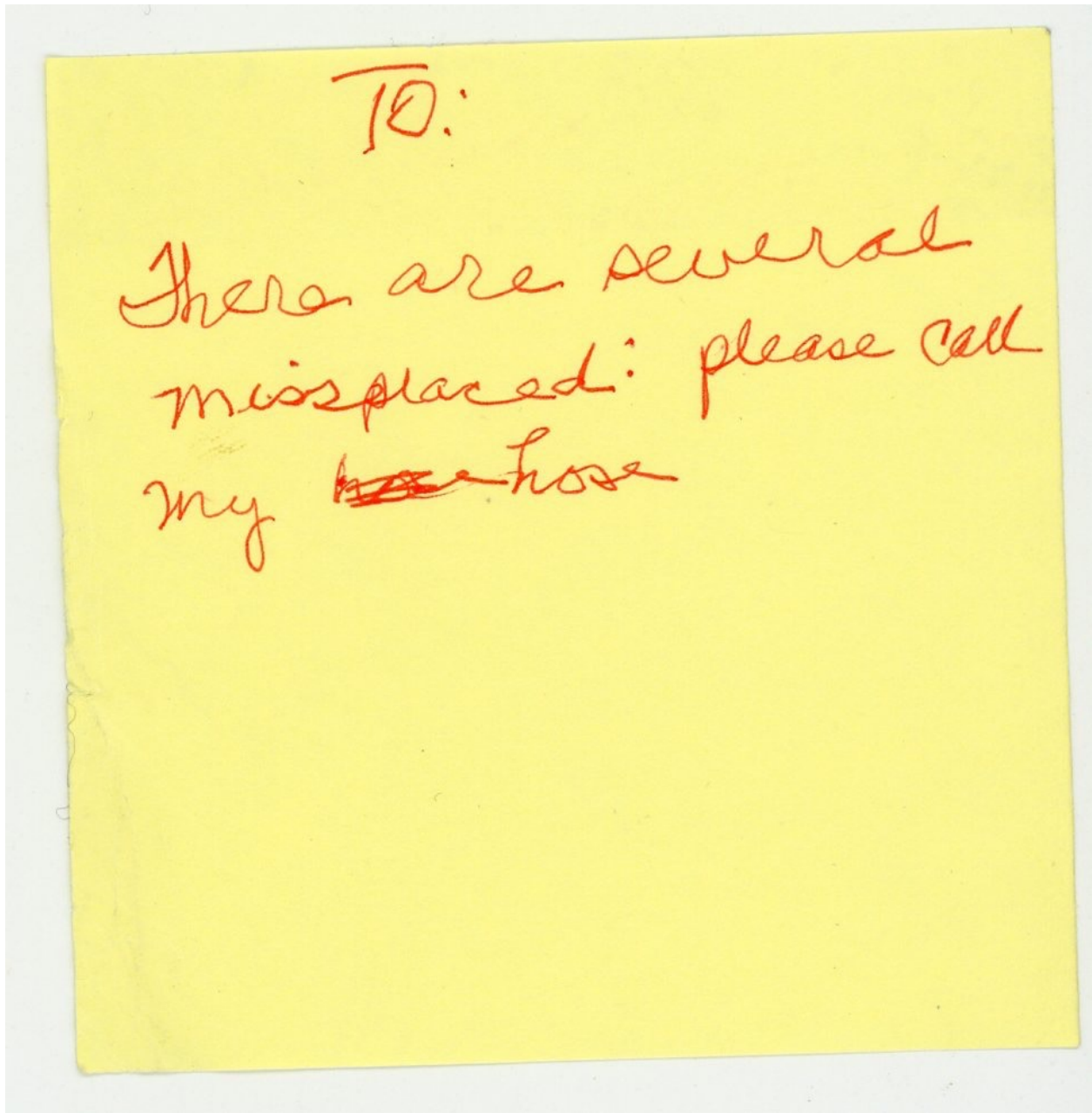
Our attachments to history, culture, place, and to one another are all relevant to the Anthropocene. Climate chaos is a result of the sociopolitical structures that have been driven by colonization and capitalism, the sociopolitical structures that we and our ancestors for many generations have called home, despite the persistent alienation and disconnection these structures have created. Climate chaos is an existential threat in multiple ways: most obviously with ecosystem collapse that threatens agricultural production, and with the changes in climate making highly populated terrains uninhabitable. But the existential threat has a trickle-down effect: not only is our daily sustenance and shelter threatened, so too are our relationships to the

histories, cultures, and people we are attached to as well. Denial of the catastrophic anxiety it can produce to feel your whole lifeworld threatened is a predictable response.

Understanding the mechanics of denial, and its relationship to attachment and supporting a felt sense of internal coherence can also help us navigate a society that uses denial strategically to cover over harm done in the era of the Anthropocene, both historically and in the present day. What people with Alzheimer's disease can teach us about navigating this existential threat brought about by the Anthropocene is that it is most important to focus on the underlying emotion – existential anxiety that threatens to sever our connection with our primary attachments to people, place, and our sense of self. Offering connection, resonance, and love can be a powerful antidote to denial. When working with institutional denial, creating these conditions means generating visions for the future that involve radical, inclusive transformation rather than staying in a place of critiquing the present and past. While critique is an important practice of inquiry and understanding, it is not the most effective cognitive / affective strategy for generating change among people and institutions in denial (Sedgwick, 2003). Indeed, the institutions that have generated the conditions of the Anthropocene have used disconnection strategically as a way to accumulate power, and denial as a way of maintaining those power differences. Silvia Federici (2018) wrote that our embodied love of and attachment to the world has been disrupted by these institutions. She described how millions of years of human evolution and adaptation to the natural world have generated in us certain needs for survival that also constitute our main sources of resistance to exploitation. Her evocative words here are worth quoting directly: "I refer to our need for the sun, the wind, the sky, the need for touching, smelling, sleeping, making love, and being in the open air" (Federici, 2018, p. 190). She explains that these needs are precisely why colonial capitalism has waged a war against our bodies, with greater violence

against those whose domination is most required for the reproduction of our society. Moving toward connection, supporting attachment, offering resonance, generating visions of abundance and connection for the future – these are all strategies of working with denial that address the underlying affect and bolster a way of being in the world that resists the ideologies that reproduce the conditions of the Anthropocene.

Chapter 3: Things: An Ellipsis and a Gathering



It is 2018, and my Mom is living with my Dad in Tucson, AZ, solidly in the “advanced” stage of Alzheimer’s disease. My Mom sits down to the dining table wherever my Dad tells her is her spot, and we eat burritos together. Bean and cheese burritos with lettuce and tomatoes were

my favorite food growing up, and I welcome the nostalgic meal during my visit to my parents in Tucson from my home in Pittsburgh. My Mom used to pack homemade burritos for me in my school lunches, and we'd eat them for dinner almost weekly. A casual food, we assembled them at the dining table from small bowls of toppings and ate them with our hands. Only now, my Mom eats hers with a knife and fork. She holds the silverware diligently, though with a gestural awkwardness that conveys that she is working through an experiment of how best to get the food to her mouth. She tries holding the fork between her thumb, index and middle fingers, then switches over to holding it in a fist. She saws the burrito with the dull knife, back and forth again and again, approaching her task tentatively. She seems to be aware she is doing something different than the rest of us, but perhaps is so consumed with the task at hand that the social awareness just lends an extra layer of stress rather than act as a clue to look at how my Dad and I were approaching the task. Maybe she has forgotten that burritos are normally eaten with hands, or maybe she hasn't identified it as a burrito at all. That she opted for the fork and knife calls back to her social etiquette: she is following a general social norm of using utensils. As someone who grew up working class in a fishing town in Alaska and then became an upper class, glass-shattering businesswoman, her social etiquette and defaulting toward something formal strikes me as a socially-conscious strategy, despite her tentative grip on the utensils.

My Dad encourages her to pick the burrito up with her hands and try eating it that way. She darts her eyes at him playfully like he's suggesting something absurd but notices his earnest expression and decides he is serious. She tries, very slowly, to pick up her burrito. It is a challenge to hold it so that the toppings don't slide out the end, and again, she approaches this tentatively. She takes a bite and puts the burrito back on her plate. Everything that my Mom does now is slow and deliberate. By the time she has taken a few bites, my Dad and I have both

finished our burritos, and we sit and talk at the table while my Mom continues eating. She switches back to using her utensils, and this time my Dad does not encourage her otherwise.

Things Forget Her

The things with which my Mom tethered herself to the world were shaking themselves free from the webbing of her being-field, including the missing word denoted with a colon in the note written by my Mom, pictured above, which reads: “there are several misplaced: please call my hose.” Eva Simms wrote of the worlding power of things: “things are deeply woven into the structures of the human body, and [...] determine locations in the web of lived space” (Simms, 2008, p. 82). When things pulled their threads from the webbing of my Mom’s lifeworld, she seemed to encounter them with more slack in the line, from farther away, and she worked to hone her focus on them with that much more energy, in an attempt to figure the thing out and to thwart the attentional demands of myriad other chaotic things in her sensorial reach. As things became untethered, missing things left an ellipsis and new things were gathered by emotional meaning.

The fork in this vignette seemed to conceal from my Mom its utilitarian history. What once she handled fluently and without consideration, required incredible cognitive attention and experimentation to master. The fork did not disclose to her the way it used to fit into her hand; it became mysterious. Maurice Merleau-Ponty wrote, “the things of the world are not simply neutral *objects* which stand before us for our contemplation. Each one of them symbolizes or **recalls** a particular way of behaving, provoking in us reactions which are either favorable or unfavorable” (Merleau-Ponty, 2004, pp. 48, bold emphasis added). Memory is a reciprocal process spread throughout our lifeworld, rather than contained inside the brain. However, when

the chiasmic pathways of recollection are fragmented and begin to unwind, the things of the world can provoke reactions of frustration, desperation, and innovation.

As my Mom lost mastery over the fork, the fork became more of a thing than an object; it regained its thingness and dislodged itself from my Mom's field of mastery, and she was forced to contend with it anew. This distinction between "thing" and "object" may seem minute, but the meanings associated with these words are important to tease apart. I refer to "things" as having a kind of animacy, which David Abram argued characterizes how people "spontaneously experience them, prior to all our conceptualizations and definitions" (1996, p. 56). Things express themselves sensuously, act as "a dynamic presence that confronts us and draws us into relation" (Abram, 1996, p. 56). Objects, on the other hand, are experienced conceptually rather than sensuously; they are domesticated in a sense. There is a benefit to objectification: it makes it much easier to use an object as a tool to accomplish a task. Experiencing the sensuous presence of a fork makes the task of eating much slower and experimental. On the other hand, approaching the fork as an object which acts as an extension of the self to accomplish the task of eating with some fluidity means bypassing the sensuousness of the fork itself, perhaps to focus on the sensuous experience of the food the fork is carrying.

In a neurotypical person, there is some degree of control and intension in how we may objectify things or encounter their thingness in a dynamic and animated reciprocal relationship, although this is highly mediated by culture. There is some intentionality behind allowing a piece of art "speak" to us, by quieting the analytical mind and opening the body to the perceptual field of the piece of art, allowing ourselves to receive and be impacted by the thing that we are engaging with our senses. In other situations, we can look at an animate landscape and imagine the objects waiting for our exploitation through practices like resource extraction. The world

around us, for the most part, is animate. Air, water, land, not to mention mosquitos and moose and daffodils, are all animate. Switching between an objectifying and a relational mode of perception is not dependent on the things themselves but relates more to how a person orients within particular cultural norms.

Indeed, US culture is one that values utilitarian objectification above the sensuous, relational perception that sees the animacy of things. We educate our children to be analytical thinkers who prioritize use-value and reward them when their default mode of perception is one of objectification. Socializing children into our society involves a steady insistence that they learn to be productive within a capitalist economy, which is reproduced through the processes of objectification and commodification. A relational way of perceiving involves recognizing the animacy of other beings and respects their autonomy within reciprocal connection. Relational perception is undervalued in the US and in many other cultures influenced by the logic of colonization and capitalism across the world; it is in direct opposition to the objectification that propels a capitalist economy forward. And as these systems have created the Anthropocene, an objectifying perception of the world is at the heart of what reproduces the era in which we have created the conditions for the annihilation of our own species. This is where the systems get under our skin, and our bodies and ways of perceiving become conduits for the larger systems of which we are a part.

Robin Wall Kimmerer connects our economy with our language in her book, *Braiding Sweetgrass: Indigenous wisdom, scientific knowledge, and the teachings of the plants* (2013). She wrote that the capitalist economy, which is characterized by commodity exchange in which a person's relationship to the seller and to the commodity is essentially limited to the moment of transaction, fits with the English language, which lacks grammar, especially pronouns, to refer to

things as animate. Wall Kimmerer wrote: “English doesn’t give us many tools for incorporating respect for animacy. In English, you are either a human or a thing. Our grammar boxes us in by the choice of reducing a nonhuman being to an *it*, or it must be gendered, inappropriately, as a *he* or a *she*. Where are our words for the simple existence of another living being?” (2013, p. 56). Note that she uses the word “thing” here how I have defined the term “object” above. Kimmerer is situated biculturally and compares US culture with her Potawatomi indigenous culture, and her use of the word “thing” here helps illustrate that the English language has a poverty of animacy to it. Perhaps for some Western scholars like myself, the word “thing” is a step toward animacy from the word “objective,” but it is still a subdued gesture toward the animacy that lives in other, especially indigenous, languages.

While Kimmerer especially emphasizes the deleterious impact the lack of animacy reflected in our language and our economy has on the rest of the living world, from mammals to insects to the rivers themselves, as we objectify and cause harm to these living beings and ecosystems, there is something still relevant here to inanimate objects like the fork my Mom was contending with in the previous vignette. The utilitarian or objectifying way of perceiving was not something my Mom could recall in that moment. It was like a horse whose saddle was taken off. The utensils seemed to have their own intentionality, as if the utensils themselves had forgotten how to obey my Mom’s will. Unwieldy reciprocity entered into the equation as my Mom fumbled with the utensils, seeming to be asking in her gentle and tentative gestures how the utensils might like to be involved in her project of eating a burrito.

Importantly, this vignette intersects with how my Mom was perceived through a lens of pathology by medical professionals as well as others in her life, including myself. The result of this shift in her perception made her approach the task of eating much slower than she used to

and using a different method than what we perceive as “normal.” From the cultural vantage point of the US, and more specifically from the “anatomy-clinical gaze” (D. H. Davis, 2004, p. 370), my Mom’s engagement with the utensils in this vignette was indicative of her pathology. The “anatomy-clinical gaze” refers to a historically situated interpretation of illness: “a previous understanding of disease was as imbalances and disequilibria, *contra* the natural body, the gaze now revealed disease as residing *within* the natural body” (D. H. Davis, 2004, p. 370). This indicates the body is read as being ill, the person themselves as abnormal, and is itself a form of objectification. The anatomy-clinical gaze can itself be seen as a symptom of the Anthropocene. And certainly, it was indicative of her deviation from the norm, including her own norm from years earlier in how she approached the task of eating. However, this is a deficit-focused interpretation that lacks any explanation about what her lived experience of using the utensils might have actually been. Although I can only offer these thoughts as a possibility, having only my own lived experience of being with my Mom during her experience of Alzheimer’s to draw on, they offer another perspective that may be less pathologizing, and which draw attention to the hegemony of our “hypercognitive” culture (Post, 2000), and its relation to the Anthropocene. What then, can our forgetful elders teach us about being, forgetting and dying in the Anthropocene? They can remind us of the animacy of the world around us, which we may have lost sight of (or never experienced in the first place) due to our socialization in political and economic systems which actively work against and encourage us to forget about being in the world in this way. The ways in which my Mom reminded me of the animacy of the world felt both riveting and disturbing, as I came up against my own disconnection from the animacy of the world.

Chapter 4: Timeless Time and Moving Spirits

Did you know your heart has a door?

Did you know your heart is a hollowed-out conch shell, a swirling entryway, around into the safe center?

Did you know your mama built the walls of your heart with her body?

Did you know she used her spirit to build the pathway into your heart?

Did you know she kept her spirit in your heart even after you were born?

Like a sea anemone's tentacle, she tethered her spirit to your heart.

Six years ago, while running through the woods on Cougar Mountain, outside of Seattle, an overwhelming feeling of simultaneous ecstasy and crushing sorrow came over me as I sensed powerfully through my spirit. My Mom was beginning her transition away from this life, entering the liminal space between this world and the next, and I felt that transition physically through her spirit slipping out from my body. It was like an out of body experience, as if I were watching it happen from above the tree line, while I simultaneously felt totally embedded in the sensations in my body, which were all pleurably humming in harmony as I glided through the woods. I knew: when she dies, a part of me will die, too; the part her that is in me. This revelation cut through my sense of past and future, and I felt as though I could run forever.

Visions of My Grandparents

A couple of years later, I again had a physical feeling in my chest of my Mom's spirit receding from my body. I recognized the feeling from that time on Cougar Mountain, and I spoke with my therapist about it. She guided me through a journey, one of facilitating the receding of my Mom's spirit from my heart: sending her spirit back to her with gratitude and a blessing, so that she may have all the energetic resources she needs for her transition. Working with the physical sensations of her receding energy from my chest, I escorted it, holding it with deep gratitude and love, and visualized sending it across space to where she was sitting in her home in Tucson. My therapist guided me to send her energy back into her heart, and when my

vision took me to where she sat, I was astonished to see my Nana standing behind my Mom, braiding her hair. Then I saw her father there, who was her rock in life, a man I never met but whose spirit I have felt deeply connected to since I was a child. Crowding behind them were my Mom's aunts and uncles, grandmothers, grandfathers, and other ancestors all fanning out in the room behind my Mom.

I was stunned. My Mom had for over a year been talking about her parents as if they were still alive. She would ask me to be sure that they had gotten home okay, or that they had found some dinner to eat, lamenting that she could not cook for them that day. I encountered these conversations uncomfortably. I had learned the popular adage in communicating with people who have Alzheimer's, a new philosophy in the field: validate whatever reality they share with you. And so, I would comfort my Mom, telling her that I had spoken with them and that they are home safely, cozy and warm. But when I told her those things, I experienced internally an incredible discord, and a horrible feeling of lying to my Mom, that left me questioning whether she could hear my deceit through my words. Furthermore, I felt like I was betraying my own reality to do so, in a way that felt violent to the validity of my own experience. I felt incredible conflict over this idea: do I negate my reality to join her in hers? Or do I negate her reality to hope to have her join mine? As her daughter, my sense of reality at its core is what she has validated for me over my lifetime. To have her join into my reality, to meet me where I was at, provided one of the most fundamental feelings of love and safety I have had access to in my lifetime. The stakes of this conundrum felt dire, and tormented me for over a year.

And then: there they were. I saw them. I saw her parents there with her! Our realities met, and neither were neglected in that moment, despite being thousands of miles apart. I experienced the reality of her perception by engaging with her on a spiritual level. And I saw that her parents

are present with her, along with a whole host of other ancestors. Mom called them to be present, for they are her guides and her comforts in her long journey through the liminal space of Alzheimer's, from this world to the next.

Co-Existentiality

The mother's body is the first house of being, a shadowy and round abode for the unborn. A great paradox rules pregnancy: are there two bodies or one? Two beings or one?
- Simms, 2008, p. 14

My position of co-existentiality with my Mom is deeply woven into my being. My life started with hers, and the most basic contours of my sense of the world begin with how she wove me into existence inside her body. "The deep space of the womb is *the first place in which the senses awaken*" (Simms, 2008, pp. 30, italics in the original). The context of the experiences I described in "Timeless Time and Moving Spirits" is grounded in my co-existentiality with my Mom. Her embodied consciousness was an invitation into the world at the beginning of my life. At the end of her life, she invited me to experience another, more spiritual, world through my own embodied consciousness.

Co-existentiality is a concept which indicates an inherent being-with; a fundamental permeability of my being with other beings, especially the particular beings you grew up with; it describes an ontological interdependence. It challenges the idea that a person is an isolated monad operating in a world of other isolated monads, where interaction is transactional between separate and whole individuals. As Simms indicated, co-existentiality describes that our perception of the world is immediately and necessarily constructed by our relational experiences with other beings; indeed, our sensory organs are developed in the context of our relational experiences. Without a relational context, babies tend to fail to thrive, and can develop sensory

integration disorders, literally unable to perceive and sense the world appropriately (Simms, 2008, p. 86). Likewise, researchers have “found that people who lived alone or who were no longer married were between 70% and 80% more likely to develop dementia than those who lived with others or who were married” (Gabbard, 2014, p. 391). Consciousness, perception, and memory are relational phenomena, and when we are removed from relational situations developmental delays or even atrophy can occur. Co-existentiality invites us into being. As this chapter seeks to uncover the theoretical underpinnings of the stories I related in the previous chapter about Timeless Time and Moving Spirits, I explore how my embodied consciousness was tethered, fundamentally, with that of my Mom’s.

The concept of co-existentiality is remembered by Western feminist thinkers, recovered from a philosophical inheritance of Cartesian philosophy, and never forgotten in indigenous ways of knowing despite centuries of colonial repression, theft and genocide (Todd, 2016). Cartesian dualism covered over co-existentiality by identifying thinking with being, famously with the phrase, “I think, therefore I am.” Cartesian philosophy leaves no room for consciousness to be intertwined, bigger than the body of an individual person. The philosophical tradition of phenomenology began to recover a relational perspective, that being-in-the-world is fundamentally being in relationship with the world, and that our sensory organs weave us into the world, giving us a field of being that exceeds the boundary of our skin, but is nonetheless rooted in the body. Maurice Merleau-Ponty critiqued the Cartesian vision of scientific inquiry for attempting to be “an absolute observer who is equally close to them all, a medium without a point of view, without body and without spatial position - in sum, the medium of pure intellect” (Merleau-Ponty, 2004, p. 41).

Embodiment is the ground of our existence, and while there is a simplicity to this fact –

indeed, we live in it every day – there are complex philosophical understandings of embodiment that substantially effect the way we live. Maurice Merleau-Ponty understood embodiment as the seat of consciousness. He discussed ideas such as body schema, intentionality, and perception as the way in which we are directed toward the world through our embodiment. In the *Phenomenology of Perception* (2002), he proposed that our ability to perceive through our senses has led some—particularly in the history of Western philosophy—to believe that our bodies are objects, or that consciousness is essentially an activity of the mind that is independent of the body. He suggested that rather than being an object, the body exists as a being-toward-the-world. The concept of “body schema” is helpful in understanding this, as Merleau-Ponty (2002) described that our bodies move not by some calculated formula thought through in advance, but as a fluid, coherent yet permeable whole in the direction of our goals. “Intentionality” is a term that he used to describe that consciousness is not a cognitive process, but a process of our bodies moving toward the world; put in simpler terms, he said: “consciousness is originally [sic] not an ‘I think that,’ but rather an ‘I can’” (Merleau-Ponty, 2002, p. 139). Our embodiment in the world is where consciousness arises, not the mind as a separate thing from the body, and it arises through engaging with the world. His concept of embodied consciousness deconstructs the binary of mind/body. While thinking, experienced as an internal monologue, may be understood as another type of consciousness, Merleau-Ponty argued that our more fundamental level of existence from which all else arises is our embodied consciousness.

Embodied consciousness arises in interaction with the world around it, as this has deep implications for understanding being-in-the-world. When we return to the body as the seat of consciousness, we return also to the lived history of that body, as a body who was born out of another body, who was nourished by another body, who learned to direct their intentionality

toward the world within the harbor of a relational field. The body schema is not just an experience of the body, but of the body in the world (Merleau-Ponty, 2002). In his essay, “The Intertwining–The Chiasm,” Merleau-Ponty (1968) described how embodied consciousness is chiasmically woven into the world, as our senses are shaped by what we perceive, and vice versa. What we perceive is shaped by our sensing it, such that the seer and the visible become indistinguishable from one another in their reciprocal structure (Merleau-Ponty, 1968). The space between seer and the visible is what Merleau-Ponty described as “flesh,” the alive, reciprocal contact that is the “means of communication” between seer and the visible (Merleau-Ponty, 1968, p. 135). I think of his idea of “flesh” as a way of indicating that the relational field is animate and is life-giving and consciousness-fostering. It is the field that we are neither completely enveloped in nor separate from; it is the co-existential framework of our becoming.

Indeed, Eva Simms (2008) wrote in conversation with Merleau-Ponty’s ideas on embodiment that cognitive thinking is a capacity that develops throughout early childhood, and infants experience an immersion in their bodily perceptions that is unmediated by cognition, such that an infant is “not merely in the world but is the world” (p. 22). She continued, noting that adults typically experience some awareness of the difference between themselves and the world they’re immersed in, but nonetheless are bodily immersed in the world. It is as if cognition mediates our being-world. In the structure of the phrase, “being-in-the-world,” we might understand “in-the” to be the work of cognition. Chiasmically interwoven, Merleau-Ponty wrote, “we are the world that thinks itself [...] the world is at the heart of our flesh” (1968, p. 136).

Observing the developmental trajectory of infants and young children reveals a particular ontological organization; one that is interdependent. Pregnancy is perhaps the most tangible example that challenges the dualism of Cartesian philosophy, and even the existential-

phenomenological thinkers that critique Cartesianism, such as Merleau-Ponty, fail to fully articulate co-existentiality (Young, 2005, p. 47). The concept upends the post-enlightenment philosophy that articulates a form of individualism that has informed the socioeconomic structures, political ideology, and framework of ethics in the West for hundreds of years. Iris Marion Young wrote: “pregnancy challenges the integration of my body experience by rendering fluid the boundary between what is within, myself, and what is outside, separate. I experience my insides as the space of another, yet my own body” (2005, p. 49). Pregnancy is only a very tangible and literal example, which Simms expands upon by describing the co-existentiality of infants with their caregivers, especially through breastfeeding. She wrote: “Milk reveals to us that the body, even in its organic dimension, is not enclosed in itself but is engaged in a meaningful web of relations. [...] Perhaps more than any other substance milk is the visible sign of the invisible, the in-between body, the chiasm, the flesh of mother and infant” (Simms, 2008, p. 15). In the stories related in “Timeless Time and Moving Spirits,” there is a folding over of my Mom’s consciousness into my own in which a meaningful web of relations from her embodied memory, and her inherited embodied memories, were revealed.

Embodied consciousness does not exist cut off from the past or future, in some kind of stark series of disconnected present moments. Rather, there is a flow from moment to moment, where the preceding moment is not forgotten, but is integrated into the present. Embodied consciousness involves a gathering up of time, as a being-toward-the-world is also a movement toward a future. Merleau-Ponty described that the body *inhabits* time and space (2002, pp.140-141). That is, space and time are not the coordinates in which we are abstractly located, but it is *through* time and space that embodied consciousness exists at all. Embodied memory therefore is a matter of living the past again through the present of the body. While some describe explicit, or

cognitive, memory as a kind of projection from the present into the past (Fuchs, 2012), I would argue that even our explicit memories (such as recalling the name of an old friend) are actually embodied, and are experienced bodily as a kind of “time travel,” where explicit memories can wash over us and conjure again the sensations of all that is tethered to that cognitive association.

Paul Ricoeur (2004) suggested that because human experience is not limited to cognition, neither is memory. If embodied consciousness is about the body in relation to the world, the same must be true of embodied memory. Embodied memory is our “lived past,” in which the body’s experiences, “anchored in body memory, spread out and connect with the environment like an invisible network, which relates us to things and to people” (Fuchs, 2012, p. 11). The body is permeable to the world in which it lives, and memory mediates that permeability, tethering us to places and other beings with whom we are bonded, anchoring our identity and providing a springboard for our actions. Edward Casey wrote that to remember “is to become enmeshed in the thicket of the past,” which he argues supports being an “autonomous agent in the world,” as an act of recognizing loved ones “consolidates social bonds that empower me in various ways” (Casey, 2009, p. 548). Here, autonomy may best be interpreted to mean the ability to act free from coercion – not independently, but *interdependently*. Indeed, it is our interdependence that makes autonomous action possible, a fact that is often covered over in our hyper-individualistic culture, another symptom of the Anthropocene.

This is clarified with a reflection on our lived experience: memories sometimes seem to occur randomly to us, but more often than not they are conjured by some stimulus in our environment. When I see an old friend, memories of times past and the ease in my body I immediately feel with her offer themselves over to me without conscious effort on my part. Sensing ease and connection, I feel welcomed and able to extend myself, to act with confidence.

The world holds our memories, and it is our chiasmic interwovenness with the world where memories are offered over to us. Memory is not simply an activity of the brain, though the brain, being an organ that is highly responsive to the environment, is involved. I would argue rather that memory is made possible because of our chiasmic relation to the world. There is a reciprocal exchange of embodied memory between the world and us.

Although intersubjectivity may be a part of our being-in-the-world, I believe it goes beyond the dyadic structure of person-to-person that the word “intersubjectivity” suggests, but rather encompasses a world. Merleau-Ponty’s description of being the world and the world being us may be a radical departure within Western philosophy, but resonates deeply with many indigenous epistemologies across the world (Todd, 2016; Kimmerer, 2013). This sociohistorical philosophical comparison is an important indicator of what colonizing cultures may forget in their move to dominate and extract, including such epistemologies in the first place, which were partially recovered by Merleau-Ponty (with help from his predecessors like Husserl and Heidegger) only by thinking through embodiment.

Cultural Ways of Knowing

Indeed, while Merleau-Ponty beautifully describes the embodied consciousness that is born out of our movement toward and chiasmic reciprocity with the world, he does little to interpret the *specificity* of the sociocultural world with which we are in reciprocal relationship. It is worth looking at memory from another side: the sociocultural and ecological specificity of the world we are woven into. Culture is a kind of intergenerational collective memory system. We pass down knowledge from one generation to the next through culture, and our memories of how we have survived become the map for the future generation to live from. Some of this is the explicit knowledge we are taught in schools and at home, but it also is the implicit knowledge of

the “habitus.” Examining the sociocultural context by way of embodiment can be helped along by Pierre Bourdieu’s (1984) concept of “habitus,” which addresses how our bodily practices are influenced by the cultures in which we are socialized. Habitus describes an embodied, pre-reflective dimension of our existence which originates in the culture (Csordas, 2015). Habitus explains the harmony of cultural dispositions among groups of people without people consciously referring back to a norm – these are the cultural norms that we embody without needing to think about it (Kontos, 2004). My own habitus may explain why I anticipate that the stories related in “Timeless Time and Moving Spirits” will not be readily understood by people situated in my cultural background, and why I am going to great lengths to explore what makes it real. My cultural habitus does not have a framework to make sense of this kind of experience.

Our relationship to culture is fundamentally facilitated with communication, including language, behavior and aesthetics. David Abram (1996) described the history of the modern alphabet and traces how language used to be born out of a reciprocal interaction with the natural world (e.g. pictorial signs, onomatopoeic words whose sounds mimicked the natural world), but evolved such that languages that use the Latin alphabet refer only to human-made signs, making the more-than-human world mostly excluded from our semiotic system. Robin Wall Kimmerer suggested that this exclusion is evident in our grammar, which reflects how we culturally structure relationships. She notes that the English language is comprised of only about 30% verbs, whereas her native language, Potawatomi, is about 70% verbs (Kimmerer, 2013). This is important because verbs refer to a kind of embodied consciousness, a *doing*, rather than a static, disembodied “thing.” She described that in Potawatomi, the word “bay,” a noun in English, would be translated as “to be a bay,” such that the water is linguistically represented, and therefore sensorially perceived, as being alive. Our language is an important system of

sociocultural memory and structures our relationships with the human and non-human world around us.

When I tell the stories in “Timeless Time and Moving Spirits,” I anticipate that my audience (Western, academic, and likely disproportionately made up of white settlers due to the white supremacy that shapes Western academic communities) will hear this as a dream at best or a delusion at worst, or perhaps a failure of my perception, because our culture, our language, our ways of knowing, do not interpret these kinds of experiences as animate, real, and spiritual.

What happens when our culture asks us to forget about our bodies and see the natural world as a commodity, as does our capitalist socioeconomic system in the era of the Anthropocene, where the needs of our bodies get in the way of the further production of capital (Federici, 2018)? When the culture asks us to deny our interconnectedness with one another and with the world? To deny the reality of our being-in-the-world, our *being-world* at all? Andy Fisher (2013), writing from a phenomenological ecopsychological perspective, said that it is this alienation from—or forgetting of—our bodies that replaces our bodily based perception of our own existence with an intellectual, fantasy-based one that we conceptualize as monologues taking place in our heads, i.e., Cartesian ways of knowing. Part of what can happen is the loss of a felt sense of being interdependent, of being permeable to other beings and to places.

It is not as if my Mom transported me through an interdimensional portal like what might be depicted in a sci-fi film. Something more mundane and literal happened, though it still felt like a radical departure from how I perceived the world before that experience. It may seem radical to trust the perception of people living with Alzheimer’s all the time. But when I could be trustworthy to my Mom – when I improvised along with her perception, stayed with her in conversation, joined her in her world – surprising gifts emerged. The gift of meeting my

ancestors was the most profound, and was one that altered my cosmology. Before that experience, I did not have an experiential relationship with my ancestors; a new spatiotemporal world opened to me. Simms wrote, “The early anchorage in maternal space remains a keystone in the depth of our spatial experience in general”(2008, p. 34). In my experience of being with my Mom while she had Alzheimer’s, she opened up a new spatial experience to me: a spiritual space. In so doing, she reminded me of my belonging to a lineage of ancestors who will have my back when I need them.

Chapter 5: Memories of Horizon

The landscape surrounding my parents' townhouse spans the spectrum from untouched desert to meticulously manicured golf course and all the range in between, of concrete, adobe style cookie-cutter townhouses with uniquely chosen desert flora landscaped to match the preference of each homeowner. My parents began visiting Tucson years ago, when my Mom could still drive, when she only had "chemo brain farts," which were concerning, but seemed within the range of normal behavior for someone her age who had endured years of chemotherapy for breast cancer. My parents loved visiting the desert, and in 2016 they finally moved there, selling their house in Portland, OR. The desert was a new environment for my Mom, one that she did not live in until after she had Alzheimer's.

My Mom sat on the couch in the living room of their townhouse for much of her waking day. Her body adapted to the shape of the overstuffed cushions, which hugged her back side and reflected her warmth comfortably back onto her skin. From the couch, she did not need to survey the back of her body for threat from the unfamiliar world in which she dwelled: it was protected, even as her long sits kept her knees from articulating and lubricating, so they sounded like crackling logs in a fire when she stood. The couch was a safe and comforting place, where she was often joined by her dog, a loyal little white fluffball of a companion who she named after her father, Jasper. The couch was a respite from the increasingly unwieldy and unfamiliar townhouse. Their townhouse had an open floor plan, so the large living room opened to the dining room and entryway and looked out on the back patio. It was a lot of space for her to keep track of at once, and she rediscovered where the hallway led every time she journeyed down it. What lay beyond her line of sight became unknown, and she filled in the gaps of her memory of the space with memories of other spaces. She slowly paced back and forth down the hallway,

looking for the set of stairs that could take her up to her bedroom. Only, in their one-story townhouse, there were no stairs, a choice my parents made together when they considered where they would like to live as they became less mobile as they aged.

I recall a visit to Tucson to visit my parents. My Mom looked out the window of their townhouse at the cacti in their back patio and the great blue skies of southern Arizona. She saw this horizon, but located herself “up North, with my Dad.” My best guess as to what she meant by “up North” was near where her parents retired and her father died in 1983, on Camano Island, Washington. It is a forested coastal area where the sky is overcast most days of the year and you’re never too far from the Puget Sound. Or perhaps she was locating herself further North and further back in time to Ketchikan, Alaska, where she grew up amidst the eagles and salmon and rain. Her father was a fisherman there and the stories my Mom would tell cast him as a community leader, a barrel-chested generous mischief-maker, who woke her up on the weekends by pounding out blues songs on the piano.

Although sometimes my Mom would look out at the desert and conjure some other, far away horizon in her minds-eye, other times she would look out at the golds and reds of Southern Arizona like a painter. One time she described the sunset to me, looking out on the eastern face of Pusch Ridge, part of the Santa Catalina mountain range visible from their townhouse in Tucson: “the mountains go pink, purple.” Something in how she said this – her grammar, but also her tone – brought the mountains to life. I felt like I was looking at the rounded backs of giant huddled animals transforming their flesh like chameleons in the magic of the dusk.

Recollection and Dwelling

Memory separates the self from total immersion in the world, giving room for

consciousness. Emmanuel Levinas wrote in *Totality and Infinity* (1969) that recollection is “a suspension of the immediate reactions the world solicits in view of a greater attention to oneself, one’s possibilities, and the situation” (p. 154). Recollection establishes the “I,” meaning that “familiarity [a mode of recollection] is an accomplishment, an *en-ergy* of separation. With it separation is constituted as dwelling and inhabitation. To exist henceforth means to dwell.” (pp. 155-156). Dwelling therefore entails both a separation from the world and an immersion or reinsertion within it as a self-conscious being that is made possible through memory.

This process of individual recollection is mirrored collectively, as Simms wrote, “In the history of human cultures, the founding of a place lies in its differentiation from the undifferentiated ‘chaos’ around it, which thus establishes a point of orientation and an ordered world of here and there” (2008, p. 31). Recollection, on both an individual and collective basis, is a process of drawing a line that establishes the boundary between here and there, me and not-me. “The separation that is concretized through the intimacy of the dwelling outlines new relations with the elements” (Levinas, 1969, p. 156). Memory makes dwelling possible by maintaining a separation of the self from the not-self, like individual threads preserved in a woven tapestry. Memory provides the space to sense that distinction, and thus the space to approach and weave into the field of being, even as memory is made possible by “living from” a place (Levinas, 1969, p. 153). To stand on the earth and to stand in oneself simultaneously is the ambiguity of embodiment, and memory maintains that ambiguity. Memory is the dashes that connect and separate each element of “being-in-the-world.” It bears repeating: “To exist henceforth means to dwell” (Levinas, 1969, p. 156).

In Western culture, memories are typically described as being “located” inside the brain of the person who is remembering. However, both Levinas and Simms open the horizon, and

locate the phenomenon of memory instead in the field of being, beyond the skin of the individual. Memory as such is comprised of the chiasmic threads that weave a person to her being-field, housed in and recalled through the matrix of places, people and things themselves. Memory dwells not in an “interior consciousness,” but is rather the threading that both separates and situates a person within the field of places, people and things they are surrounded by and which they gather into a configuration of identity. Dwelling therefore is an act of collecting again, re-collecting, the pulse of the world, which vibrates through the being who is held separate from and simultaneously situated within the world with memory.

Specific memories gather a concretized self. A self who has a history, particular likes and dislikes, particular identities, ideologies, and attachments. However, while specific memories are totalized concretizations of things that happened in a past chronological time, the *faculty* of memory is the thread that weaves us into the field of being. Recollection is the tethering that dwells us in the world.

Dwelling in Alzheimer’s, Alzheimer’s Embodied

What happens to a person who is losing her memory, if dwelling is an act of recollection? She becomes unwound from the world, in a sense; the apparent exterior here-and-now may not match the interior experience of here-and-now. In the vignette at the start of this chapter, my Mom was physically located in Tucson, and yet she felt as if she were “up North,” in a very different landscape. This *dwelling elsewhere* resulted in fissures in a shared lifeworld with the people around her, even while her embodied selfhood persisted (Kontos, 2012). My Mom continued to dwell, but the world she located herself within was not always in the here-and-now that the people around her experienced.

My Mom sought comforting spaces as her secure position in the webbing of time and place loosened with the progression of her disease. Her experience of furniture, rooms and horizons changed as a result. “In a very general way, the key problem of dementia might be described as the loss of a common shared world of meaning, that is, the loss of a common home” (Dekkers, 2011, p. 292). If she was losing her place in a “common” home, what was she experiencing instead? She negotiated a novel world from the compass of her embodied memories, which became dislodged from their specific positions in the chronological and spatial history of her life. It must be underscored though that her dwelling in another world, different from the one experienced by the people around her, was nevertheless a shared lifeworld, a common home with other beings, most notably her parents, who she often discussed. As the world around her began to feel unfamiliar, she located herself in another home.

Cradle and Comfort

The home, as a building, belongs to a world of objects. But this belongingness does not nullify the bearing of the fact that every consideration of objects, and of buildings too, is produced out of a dwelling.

-Levinas, 1969, pp. 152-153

The place my Mom was in did not adhere to her cognitive schema of her present location. When my Mom was searching for the stairs to her bedroom in her single-story home, her embodied memory knew how to get her to a comforting resting place, only the floorplan of their current home did not match that memory, which arose out of another time and place. Gaston Bachelard wrote:

But over and beyond our memories, the house we were born in is physically inscribed in us. It is a group of organic habits. After twenty years, in spite of all the other anonymous stairways, we would recapture the reflexes of the ‘first stairway,’ we would not stumble

on that rather high step. The house's entire being would open up, faithful to our own being. (1964, 36).

The stairs up to her bedroom, the threshold to where the demands of her waking world could be temporarily released, were inscribed in my Mom's body, and she navigated from that felt compass. She looked again for that threshold, but it took a different and unfamiliar form in this home, one which she had not been able to incorporate into her embodied schema to recall again as needed. And so, recollection failed her, and the house in which she lived closed off its homeliness to her, retracting its hospitable welcome.

My Mom knew, in this example, what function she was looking for: she wanted to find a place to rest. However, the form of her home did not feel familiar, so she could not trace along the contours of her house to find her way back to the function she sought. The phenomenological philosopher of ecology, David Abram, wrote: "The body *itself* is a kind of place—not a solid object but a terrain through which things pass, and in which they sometimes settle and sediment" (Abram, 2011, p. 230). The terrain of my Mom's embodied consciousness had begun to sift free those things which had settled, dislodging them from their familiar configurations.

Dwelling with Alzheimer's

For my Mom, the outside world shuffled, and the horizon she gazed upon could be any number of horizons from her past. The horizon seemed to be conjured by my Mom's emotional stirrings: what felt emotionally relevant was where she felt she resided in space. My Mom's tendency to replace the horizon she was looking out at with a meaningful one from her past made sense as she tried to answer the question: where am I? She answered based on where she felt it was likely she was, based on where her heart had most been called. The time that she spent visiting Camano Island, about hour from her home of 30 years in Seattle, was of immense

emotional magnitude. Her parents retired on Camano Island, and only lived there for a few years, during which time she gave birth to her first child, my older brother, Steve. Six months later, her father died from pancreatic cancer, an hour after my Mom promised him that she would take care of her mother, who was showing signs of developing Alzheimer's herself.

As her memory of the horizon became conceptually disorganized, my Mom compensated with poetry to tie together the disintegrating schemas of her cognition. As a result, she experienced and invited others around her to feel again "the birth of the landscape," or "the feel of perceptual experience itself" (Merleau-Ponty, 2004, p. 41). When she said, "the mountains go pink, purple," rather than organizing her description from an analytical schema where the mountains receive the effect of the setting sun, and the origin of change is the sun going below the horizon, she described how the mountains themselves transform. The specificity of the mountains, separate from the sunset, animated them, dancing apart from their adherence to the landscape. Bachelard describes that poetic imagery precedes thought and instead arises from the soul: "To specify exactly what a phenomenology of the image can be, to specify that the image comes *before* thought, we should have to say that poetry, rather than being a phenomenology of the mind, is a phenomenology of the soul." (1994, p. 4). My Mom's soul recognized the vitality of the changing mountains. Through my Mom's poetic gesturing toward the landscape, she restored the earth with a mystical, alive quality that has often been stripped from it with the Western perspective of scientific objectivism. David Abram wrote: "The body is [...] a sensitive threshold through which the world experiences itself, a traveling doorway through which sundry aspects of the earth are always flowing" (2010, p. 230). My Mom's embodied experience of the landscape through her position of Alzheimer's allowed the earth to experience itself once again

as alive. She also shared that animacy of the earth with the people around her, including me, giving me a sense of enchantment with the landscape.

Would the experience of place become as dislodged in a person who had been embedded within a single landscape during their lifetime? I wondered whether the fact that my Mom had moved so many times to such different landscapes over the course of her life influenced her experiences of the horizon in Tucson. Moving between such varied landscapes of Alaska, Washington, Oregon, and Arizona was available to my Mom because of her upward class mobility throughout her lifetime. But for many people in other cultural and socioeconomic locations, they might live with the same horizon for their whole lives. Although my parents enjoyed the warmth of the desert and chose to live there, it is possible that their moves to different landscapes provoked more disorientation for my Mom as she had Alzheimer's. Connection to place can invoke a feeling of belonging whereby one can "feel at home"; it is "a landscape of memory, thought and imagination" (hooks, 2009, p. 221). As Yi-Fu Tuan argued, we strengthen our sense of self by accessing our imaginative and material past; objects anchor time, and place, though shifting, allows us to recapture our personal history (1977, p. 187). As my Mom faced insecurity about her sense of self in a place she had only lived in with Alzheimer's—that is, a place she struggled to create new memories of belonging to due to the disease making it difficult to consolidate new memories in general—she found a strengthened sense of self in her memories of other places to which she used to feel a sense of belonging.

Finding belonging in a shifting horizon is an ontological skill that will serve us well as we navigate the climate crisis of the Anthropocene. As the places we dwell in and are attached to undergo increasingly rapid changes in flora and fauna, including more frequent and intense dramatic events such as wildfires and hurricanes, our ability to root into a felt sense of being at

home when the world around us feels unfamiliar will be crucial for our survival. Our most forgetful elders show us that even when profoundly disoriented, it is possible to anchor into a felt sense of being at home in the horizons we have dwelled in throughout our lives.

Chapter 6: Take Me on a Long Walk off a Short Dock

My Mom's mother, who my brother and I called Nana, had Alzheimer's, too. She eventually died from the disease when I was 10 years old, and I don't have any memory of Nana without Alzheimer's – that was how I always knew her. My Mom was Nana's primary caretaker, as her father died from cancer very early on in the course of Nana's illness, and my Mom was an only child. My Mom tried to preserve her mother's independence for as long as possible, and Nana lived in her own house in our neighborhood when I was a little girl. My Mom would cook for her and do her laundry, on top of having two small children and a demanding job. When we would visit Nana at her house, my Mom would enlist me to crawl under the bed and recover the silverware and other trinkets that Nana would hide there. She thought that people were trying to steal her belongings, so she would hide them under the bed, between the couch cushions, and in other unexpected nooks and crannies throughout her home. I took pleasure in searching for these things; it was a scavenger hunt that was helpful to my Mom.

After a small fire in Nana's house when she forgot to turn the stove off, my parents moved Nana into our house. I was young, and I don't have many memories from the time when she lived with us. After a while, my parents moved Nana into an assisted living home in a suburb of Seattle. Despite being able to afford their laundry services, my Mom elected to continue doing her laundry every week, as a way to stay in relationship and regular contact despite the long drive. Naturally, my Mom felt ambivalence about visiting Nana; it was painful. Doing her laundry kept her accountable to making frequent visits. It wore my Mom out.

My memories of Nana are mostly of visiting her at the assisted living home. I didn't like going there, but I liked spending time with my Mom on the drive. Nana lived in the locked memory care wing of the large facility, the kind you needed to type in a code to get through the

door. The place smelled like canned green beans, stale humidity and baby powder. Sometimes I would breathe through my mouth while I was there to avoid smelling it. Nana didn't talk much, and when she did, it was difficult to follow, her words trailing off, falling in a pile off to the side. I could sense that she was confused, and sometimes irritated or upset, but she couldn't explain why. As a young child, I couldn't understand why she might have felt those things. I feared her cloudy and upset affect. Sometimes, though, I would sit near Nana and we would lock eyes, and it would feel like we were connected. Her eyes could smile and love deeply, even after her language stopped making much sense. Nana died in 1998. I remember my Mom getting a call that Nana had had a grand mal seizure. In my young mind, I imagined a hurricane sweeping through the inside of her body. She died the next day.

My Mom was a daddy's girl - her father was her hero, and his death from cancer in 1983 was devastating to her, especially because he died 6 months after she gave birth to her first child, my older brother. On his death bed, my Mom promised her father that she would take care of his wife. My Mom upheld that promise, but taking care of Nana was hard. I think it was a combination of the particular ambiguous grief of losing someone to Alzheimer's, and that my Mom was expected to (and expected herself to) do it all—glass ceiling-shattering career and all the reproductive labor of taking care of a family and a home. Those years were overwhelming to my Mom.

Underlying all the exhaustion, I think my Mom felt fear. On a gut level, my Mom feared the possible future of getting Alzheimer's herself. Looking at her mother was like looking at her own worst fears of what could happen to her. The fear was visceral. She never expressed it in a vulnerable or confessional way to me, but she told us hundreds of times over the years: "if I ever get Alzheimer's, take me on a long walk off a short dock." She did not want to die that way

herself. She practically made us promise her that we would take her to a dock and throw her in if we had to. Although she would say it somewhat tongue-in-cheek, it was never entirely a joke. Sometimes difficult truths can only be joked about.

I wish I knew what in particular made her say that. Was it her fear of not recognizing us? Of being dependent on others? Of requiring lots of time and money for care? Of not being a “productive member of society”? Of losing her identity as a woman in charge, both at work and at home? Was it her grief about her Mom expressing itself in the language of fear? All of these things combined? Something entirely different? She shared this refrain enough that when my Mom finally was diagnosed with Alzheimer’s disease herself, it loomed in the back of all our minds.

How it loomed in my mind was amplified by the context of my own life at the time when my Mom was diagnosed. I was working as an end-of-life doula for two years, assisting a man named Mark, who had ALS, with all aspects of his dying process. I was intimate with death in those years. On April 20, 2015, Mark ended his life using physician assisted dying. I sat with him and his wife that day, as he administered a lethal dose of medication through his feeding tube. It was profoundly sad, as any death of a loved one is. But his death was marked with his autonomy, and I believe that it was an empowering decision for him to make in the face of the loss of control of every muscle in his body, including his diaphragm. He would have died before too much longer, in a much more terrifying way, most likely by choking, as swallowing even his own spit became nearly impossible.

In what I can only describe as an experience of the Universe laughing mirthfully, within 30 minutes of Mark dying, while I was beginning to make calls to his loved ones to let them know about his passing, I received a call from my Mom, frantic. She had been admitted to an

inpatient geriatric psychiatric ward. In the months leading up to Mark's death, my Mom began to experience a phenomenon known as Capgras Syndrome. It is a relatively rare phenomenon in which a person believes that those they are closest to are imposters. It happens most often in people with neurocognitive disorders or traumatic brain injuries. She had been experiencing this with my Dad; she thought that someone who looked like my Dad had assumed his identity and was lying about who he really was. My Mom was terrified about this, naturally, and she tried to defend herself, sometimes by hitting him. Although my Dad was stronger than my Mom, the situation was unsafe for both of them, and eventually after a particularly intense day of this, my Dad called 911. The paramedics took her to a psychiatric hospital. It just happened to be the same day, the same hour, that Mark died. That was the day that my Mom was officially diagnosed with Alzheimer's disease.

And so my Mom's insistence over the years that my family take her on a long walk off a short dock if she ever got Alzheimer's registered to me in a new light. The ethics, of course, were different with my Mom at this point, because unlike with Mark, it was unclear whether she would be able to fully understand the implications of physician assisted dying. Not to mention that it is illegal in the United States for people who have any kind of dementia. But over time, it became something that I regretted not talking with my Mom about earlier in her journey, when it may not have been legal, but it may have been ethical for her to consider seriously for herself. She wouldn't have been the first person to make such a decision, facing a diagnosis of Alzheimer's. The fear of that emotional confrontation, and the taboo of the subject, held me back from broaching the subject with her. I don't know for sure, but I wouldn't be surprised if the same things held her back from bringing it up when she was in the early stages of the disease.

I remember reading, shortly after Mark died and my Mom was diagnosed, an article in

the New York Times about a feminist psychologist named Sandra Bem. She had been diagnosed with Alzheimer's, and decided to end her life before the disease did. The article detailed how she timed the end of her life to be in the "sweet spot" to maximize the length of her life, but to administer the lethal medication before she lost her ability to clearly comprehend what the implications would be (Henig, 2015). Because it was not legally sanctioned by any Death with Dignity laws in the US, Sandy Bem's death was considered suicide. Part of what moved me about that article was the sense of joy and agency that Sandy seemed to possess about her decision. The conversation was out in the open.

Late into my Mom's disease, my Dad and I confided in one another about the moral quandary we felt about this. We both knew that she never wanted to live this way. She told us again, and again, and again before she ever got sick. This question didn't just animate the hypothetical of physician assisted dying, which we both knew was out of the question due to her inability by then to participate in informed consent. Rather, it showed up in increasingly subtle ways as we made choices about *prolonging* her life. Should she continue taking medication intended to slow the progression of Alzheimer's, knowing that it might add 6 more months to her life? Would those 6 months be a gift or a burden to her at this point?

When we try to honestly represent her wishes, do we remember her wishes from before she had Alzheimer's? Or do we try to understand what those wishes might be in the present? And if we try to understand what those wishes might be now, how do we do that? By the time my Dad, brother and I started to talk about this openly, my Mom struggled to participate in conversations at all. We could not ask her directly by then. All we could do was try to assess the quality of her life, balancing her past wishes with our sense of her experience in the present.

By then, she took pleasure in simple things; petting the dog, sitting on the couch with us,

coloring in her coloring book. Every night, my Dad and her would sit on their patio with a glass of wine (in my Mom's cup, dealcoholized wine, as alcohol made her disoriented and agitated) and watch the sunset. There was joy in her life, moments of pleasure, and moments of connection. Was it joy she would choose for herself?

Physician Assisted Dying

This story about my Mom demanding that we take her on a long walk off a short dock elicits multiple theoretical threads worthy of inquiry. Of course, the issue of Physician Assisted Dying (PAD) is the subject of an ethical and cultural battleground in the United States and in many places around the world. In the US, there are 8 states plus the District of Columbia where PAD is legal as of 2020, however all of those places exclude people with Alzheimer's disease and other dementias from using this kind of care. Under the structure of current laws, the simple reason for this is that a doctor must determine that a person has less than 6 months to live in order for them to prescribe life-ending medication, and by the time a person with Alzheimer's is likely to be within 6 months of their death, they would no longer be able to provide consent due to the cognitive declines typical of the disease in the late stages. For people with Alzheimer's disease, there is fundamentally an issue of timing when it comes to being excluded from legal access to PAD. How did PAD come to have the timeline around 6 months before a natural death? And how did PAD come to be a phenomenon to begin with? Cheryl Mwaria wrote that culture plays a significant role in physician assisted dying, and that "focusing as it does on the individual, our current approach to death seems to presume culture is irrelevant. Nothing, however, could be further from the truth" (Mwaria, 1997, p. 862). What I aim to unpack here is an exploration of the cultural situatedness of PAD, in order to locate the reasons why people with

Alzheimer's are excluded from it.

Physician-Assisted Dying is a Cultural Artifact

Michael Cole described that the first basic principle of cultural-historical psychology is that people mediate their interactions with the world and one another through artifacts (Cole, 1996, p. 108). The definition of "artifact" should be taken broadly, to include material, ideological, and other types of things like language. Importantly, artifacts are not only tools that do something to the world, they also do something to the user of the artifact: "every human being has her or his subjectivity and mental life altered through the process of seizing meanings and resources from some sociocultural environment and using them" (Shweder, 1990, p. 2). Conceptualizing PAD as a cultural artifact situates it into a cultural-historical framework of meaning, where it "accomplishes" more than simply the death of a person.

To begin to see PAD as a cultural artifact, it is helpful to distinguish it from other forms of death, including other forms of suicide, and even from suicides of someone experiencing a terminal illness or extreme old age who uses another method, such as refusing treatment or electing to stop eating food or drinking water. PAD describes something very specific, and the Death with Dignity organization, which has advocated for the legalization of PAD in states around the United States, describes eligibility to use PAD as such:

To qualify under Death with Dignity statutes, you must be an adult resident of a state where such a law is in effect; mentally competent, i.e. capable of making and communicating your healthcare decisions; and diagnosed with a terminal illness that will lead to death within six months, as confirmed by two physicians. The process entails two oral requests, one written request, waiting periods, and other requirements. (Death With Dignity, n.d.)

If a person fits all of those eligibility requirements, they will be prescribed a lethal dose of medication, though what exactly is prescribed varies by medical provider.

The language used to describe PAD is extremely specific, and controversial, and adds a layer to how the literal use of PAD gets taken up in our cultural imagination. Death with Dignity, an advocacy organization working to legalize PAD in more states in the US, notes on its website that they prefer to call PAD “death with dignity,” but that other acceptable terms include “physician-assisted death, physician-assisted dying, physician-hastened death/dying, aid in dying, physician aid in dying, and medical aid in dying” (Death With Dignity, n.d.). They carry on, noting that “Incorrect and inaccurate terms that opponents of physician-assisted dying use in order to mislead the public include: ‘assisted suicide,’ ‘doctor-assisted suicide,’ ‘physician-assisted suicide’, and (active) ‘euthanasia’” (Death With Dignity, n.d.). It is worth noting that while physician-assisted suicide is merely a different name for the same thing as PAD, euthanasia is actually a slightly different act with important connotations. The European Association of Palliative Care defines euthanasia as what happens when “a doctor intentionally kills a person by the administration of drugs,” while PAD is when “a doctor helps a person to commit suicide by providing drugs for self-administration” (Materstvedt et al., 2003). The terminology with which we describe PAD impacts how we understand the act, and the connotation with or distancing from “suicide” is key in understanding what role(s) PAD plays on a cultural level. This brings up questions of the culturally specific meanings and connotations with the term “suicide,” which both sides of the debate use as a negative, taboo term. PAD does not attempt to undo the taboo of suicide; rather, it attempts to distinguish itself from suicide such that it avoids carrying the same associations of shame, despair, and tragedy.

Rather, PAD is framed as hastening death for somebody for whom it is already immanent

and inevitable, with the intention to reduce suffering associated with many end-stage terminal illnesses. The right to die is one of the most compelling arguments for the expanded legalization of PAD, as “it draws on the principle of autonomy, which is highly valued in a democracy” (Tomlinson, Spector, Nurock, & Stott, 2015, p. 724). The reduction of suffering is focused primarily upon physical suffering, as many states in the US require an evaluation by a psychologist to rule out psychological drivers behind the wish to end one’s life with PAD, and the presence of depressive and certain other psychological disorders can disqualify potential candidates of PAD. This distinction between physiological and psychological drivers of the wish to end one’s life is a particularly fraught element of the cultural debates over the legality of PAD, as some have argued for the legality of PAD for psychiatric illnesses including treatment-resistant depression, which is legal (although rarely approved) in the Netherlands and Belgium (Steinbock, 2017). The Netherlands is also the only country in which PAD is a legal option for people with Alzheimer’s disease and other dementias (D. Jones, Gastmans, & MacKellar, 2017). Alzheimer’s disease is in an odd middle ground with regards to the split between physiological and psychological disorders driving the decision to end one’s life before the disease does. Unlike psychiatric illnesses, Alzheimer’s disease is a terminal illness that has a clear biological etiology; however, its primary symptoms are in the domains most often claimed by psychology: cognition, behavior, and social relationships.

Ecological Developmental Model of PAD

Urie Bronfenbrenner originally published *The Ecology of Human Development* in 1981, which has since been widely influential, including being significantly taken up in the 2017 APA multicultural guidelines (American Psychological Association, 2017). His dynamic, bidirectional ecological model of human development suggested that we seriously analyze how the context of

human experience is left out of most accounts of developmental psychology (especially coming from a Piagetian model), and that furthermore, context is complex and dynamic, and should be conceptually broken down into several interacting levels to better see its nuance. Bronfenbrenner wrote, “The ecological environment is conceived as extending far beyond the immediate situation directly affecting the developing person” (1981, p. 7), giving a wider lens of analysis for understanding individual experience. His model includes several levels that are like concentric rings around the individual, that extend from internal experience of an individual through many layers of relational contexts from immediate family to community, institutions, sociopolitical systems, cultural ideologies, and global environments.

This ecological model of development allows us to see a more dynamic picture of how PAD may be taken up in an individual’s life. As Susan Wolf put it in her feminist analysis of the issue, “the debate over whether to legitimate physician-assisted suicide is most often about a patient who does not exist – a patient with no gender, race, or insurance status” (1996, p. 282). By using an ecological approach to understanding context and identity, we can better understand how PAD might impact real people situated in their specific sociocultural context. Furthermore, we can get a better understanding of the ways in which PAD does not exist merely as an individual choice, but impacts the individual through multiple contextual layers. Cheryl Mwaria (1997) urged people to consider the impact of culture on the debate about expanding legal access to physician assisted suicide. She argued that in considering physician-assisted suicide, “the real challenge lies in understanding the nature of culture itself. By definition, culture is learned behavior pertaining to norms for what is considered proper, moral or even sane; as well as values, customs, beliefs and artifacts that comprise the knowledge and technology by which we adapt, or fail to adapt, to the physical environment” (1997, p. 859). She called attention to the

sometimes unconscious impact of broader contextual factors on an individual's choice to end their life with PAD. She cautioned, "What seems on the surface to be a voluntary act, the rational decision to end one's life, may actually be the product of social expectations" (p. 862).

Considering social power dynamics, systems of medical care, governmental structures that impact caregiving and access to care such as Medicaid and managed care, the "right to die" argument becomes more complicated, and it becomes complicated in unique ways for people with Alzheimer's disease. An international systemic review of the literature on attitudes toward PAD for people with dementia found that "sociodemographic factors influence attitudes toward assisted dying," including factors like age, ethnicity, gender and religion (Tomlinson & Stott, 2015, p. 10). Arguments about the impact of culture and other layers of the ecological model of development help us pay attention to things like how gender roles might impact the level of comfort a person might feel in depending on others for care. This example remains relevant for people with Alzheimer's disease, however there are additional and unique layers to consider with regards to PAD being used by people with Alzheimer's and other dementias.

Arguments that this dissertation has already reviewed about the debate on selfhood in people with Alzheimer's disease are particularly relevant. Although I argued in the literature review section of this dissertation that people with Alzheimer's disease have an ongoing embodied selfhood, there is no doubt that there are major changes in the self that occur over the course of the disease. Indeed, that there is a debate about whether or not the self persists throughout the course of the disease is an important cultural factor in considering the unconscious ways in which people with Alzheimer's disease may be influenced in deciding whether or not to use PAD were it legal. The fact that Alzheimer's disease itself is often stigmatized and people with the disease are often devalued in our hypercognitive culture could

potentially influence a person to feel that they would avoid profound suffering if they could die before the disease runs its full course. In other words, part of the suffering experienced by people with Alzheimer's disease includes being socially devalued, which can be understood as "excess disability," a concept I discussed in the literature review of this dissertation, which articulates the "discrepancy that exists when a person's functional incapacity is greater than that warranted by the actual impairment" (Brody et al., 1971, p. 124). Insofar as this aspect of suffering might influence a person with Alzheimer's disease to want to use PAD, a more ethical intervention than PAD would be an intervention on a cultural level to reduce stigma and increase a value of neurodiverse people, including people with Alzheimer's disease. Of course, this is not the only element of suffering that people with Alzheimer's disease experience, however it is an important cultural consideration of the use of PAD with people who have Alzheimer's.

The same systemic review mentioned above found that issues of capacity and dementia severity are important considerations, and that people with dementia and their caregivers "held reservations about euthanasia in advanced dementia and were instead supportive of PAS [Physician-Assisted Suicide] in the early stages of dementia" (Tomlinson & Stott, 2015, p. 17). Being able to participate in informed consent can become impossible in the late stages of the disease despite the presence of a persistent embodied selfhood in people with Alzheimer's disease. It comes down, once again, to the issue of timing: while people in the early stages of Alzheimer's can participate in informed consent, at that point they are too far from death to be eligible to legally use PAD. However, even people in the early stages of the disease are vulnerable to social pressures that can influence one's autonomy in consenting to PAD. The negative stigma of simply having Alzheimer's disease is likely to exert a degree of pressure that can be difficult to mediate.

This raises questions about how we structure legal access to PAD. Why is it that 6 months is the legal window within which one can use PAD in the US? Might people with Alzheimer's disease and other dementias deserve to have access to PAD earlier should they wish to use it? The intent of this chapter is not to advocate one way or the other for expanding legal access to PAD to people with Alzheimer's disease, but rather to explore the complexity of the issue and situate the debate within broader cultural considerations. Personally, I feel uncertain about my stance on this issue even after further research. While it was clear that my Mom wished in her earlier years to die before she had advanced Alzheimer's disease, this dissertation demonstrates the value and gifts that she offered to the world even while she was in the advanced stages of the disease. And by the time she was later into the disease, it did not at all seem clear that she would have rather not been alive for her final years. My Mom's experience, however, is not indicative or prescriptive of the experience of others living with Alzheimer's disease or other dementias, and is highly influenced by her specific cultural situatedness as a white woman who thrived in our hypercognitive culture, who identified as a caregiver through her roles as a mother and daughter, and who witnessed her own mother's decline and eventual death from Alzheimer's disease within our system of managed medical care.

What is clear through this exploration is that the medical industrial complex, interwoven as it is with our legal system, highly regulates who can access what type of care, when they can access it, and what counts as qualifying for access, often without consideration for cultural situatedness and the implicit pressure people may experience based on their socialization within certain culturally delineated roles such as gender, race, or disability status. Although this chapter focuses specifically on the legal and medical structures in the United States, there are insights relatable to dying in the Anthropocene, in particular regarding the meanings attached to death

that motivate arguments on either side of the debate about PAD. That the medical industrial complex has such a degree of influence and power over our choices about living and dying is itself a symptom of the Anthropocene. Whether it is good or bad, something people should have control to hasten or delay, when and how it is better to seek death than to seek ongoing life, and how to navigate issues of consent and representation for beings who cannot advocate for themselves within our current social structures are all relevant debates, and the answers are complex and perhaps can never be settled entirely. Expanding these debates onto the level of the human species and our interdependence with an animate biosphere, is relevant to this moment of existential crisis in the Anthropocene. Roy Scranton wrote, “it may be that we have crossed the summit of our knowledge and power, and the brief explosion of human life in the Holocene will turn out to have been as transient as an algae bloom. It may be, on the other hand, that we’ll find a way to survive in the Anthropocene, perhaps even find ways to maintain human civilization in some recognizable form” (Scranton, 2015, p. 118). As we make choices about whether and how we collectively live and die in the Anthropocene, we must represent the other-than-human beings who cannot self-advocate within our social structures. Navigating the complex ethics of these choices is not straightforward at all.

Chapter 7: Time Traveling

When my Mom stopped eating for 4 days in February 2019, the owner of the assisted living facility into which we had moved her only a month prior suggested it was time to get hospice services for her. Although she had been engaged in profound transformation for years already, I was not ready for this suggestion, and suddenly I was forced to consider just how immanent her death could be.

I did not want my Mom to die! I felt confused, devastated, and scared. And then a wave washed over me: awe. She is twisting the folds of the skin between this world and the spirit world. Twisting it toward an opening for her passage. It felt so much like a birth - something within her set in motion this process, and everything in her lifeworld was contracting, making space, allowing, saying “yes,” breathing with and for her. A movement that was bigger-than was casting us all to our knees, rhythmically sighing, crying, breathing with and for her. Moving her spirit through us. Letting go where we could, though parts of us rebelled and pleaded for more time. Parts of us remembered the softness of her skin and wonder whether they’ll ever touch anything so soft again. A softness our hearts could touch. A softness we shepherd through the movement.

My Mom died on April 20, 2019. My Dad was with her, holding her hand, and I was at home in Pittsburgh, my brother at his home in Portland, OR. There was something that felt removed from time when she died. That night, it felt so unreal to learn of her death in my bedroom around midnight, as if news like that should only be delivered in special places away from everyday life. My grief about my Mom had been with me for years already, a blend of anticipatory grief and an ongoing series of losses with the transformation of our relationship as her disease progressed. I had tried to tame my grief over those years to have some semblance of

normal life, although the journey to this point had been very difficult already. In recent years, my grief had been coming out sideways; often when I felt unrestrained joy, I would begin crying, the grief having found an escape hatch. I tried to let myself grieve in intentional doses, but I had a filter. I felt I needed a filter to carry on with my own life over those years, like a dam that regulated the flow of a river.

When she died, the dam broke.

For weeks after her death, I was inundated with vivid memories of being with her throughout my lifetime. I did not try to remember these things; rather, I felt as if I were simply a conduit, and my grief had its own intentionality, flowing through me with force. I found myself in my parent's bed again as a young child, giggling together with my Mom as we cuddled on a weekend morning, the sheets illuminated by sunlight streaming through the window, the smell of waffles and bacon drifting up from the kitchen downstairs where my dad cooked breakfast, still in his fleece bathrobe. Joy. I found myself storming up the stairs in high school away from a fight with my Mom, and after a few minutes, her following me to make peace about whatever it was we were fighting about. These and hundreds, maybe thousands of other memories were more vivid than anything happening around me, flowing from one to the next. My grief made the world I was actually in feel colorless, and my body felt like it weighed a thousand pounds in those weeks. But in the flood of memories there was life and levity, and I time travelled from memory to memory, an orangutan in the jungle of my Mom, my world-maker. A whole ecosystem of memories to dwell in.

My Mom had taught me during her time with Alzheimer's about time travel. At first, I found it scary, being shuttled with her into her memories of her parents, who she often thought were still alive. One minute we would be talking about her childhood as if she were still in high

school, needing to prepare for an exam, and the next we would be in her adulthood when she was caregiving for her own mother, who had died some 20 years prior. Being in conversation with her meant you had to be ready to time travel at any moment. It required a receptiveness beyond the frame of my own perception and flexibility in one of our most basic forms of being oriented to the world: knowing where you are in time and space.

At first, I felt rigid and resistant to time traveling with her. I remember having a dream about it in 2017. My journal from the time wrote: “I dreamt I went through the portal, down through some kind of webbing, below. Landing in Disneyland after dark, but not the way it is marketed. It is disorienting like a state fair after too many rollercoaster rides, clownish music distorting, childhood imagery suddenly frightening. I’m with my Mom, and I’m searching for her at the same time.” It was so disorienting to time travel with my Mom; to meet her where she was at, wherever and whenever she was at from her point of view. I felt as if I might lose my own grip on the present, and on my sanity, in the process of trying to join with her.

Over time I became more comfortable time traveling with her. I’m not sure if I got used to it, or if it just started to feel less scary. Wrapped up into the time traveling was an engagement with my grief: my sadness, anger, confusion, and simple resistance to the fact that my Mom had Alzheimer’s. To join with her was to allow all those things into my experience. To be present with her required being present with my grief. Time traveling with my Mom meant that things were not how they used to be between us.

I don’t remember how many days passed between when my Mom died and when I flew to Tucson with my partner Kyle to be with my family. I do remember feeling completely useless though. My friend Autumn Marie came over to help me pack my suitcase. Kyle sat in the middle seat on the plane while I sat at the window, him guarding me from having to interact with any

other people, receiving the in-flight snacks for me. I remember thinking about all the other bereaved people who fly every day after receiving shocking news of a loved one's death. I felt a solidarity with this fragile, invisible community.

Within a week following my Mom's death, my family had a viewing so we could say goodbye to her body before she was cremated. We planned for a larger celebration of life a couple months later, so the viewing was just my Dad, my brother, my brother's partner Lisa, Kyle, and my Mom's cousin David. Saying goodbye to my Mom... there was an impossibility of that day. My Mom, the creator of my lifeworld. I can't describe that experience with many words, nor do I want to let my readers into the full depth of that memory; it is mine to keep. However, at her viewing I cried with a wide open heart, no holding back. My Mom's cousin David commented that it was as if each gasping breath I took as I sobbed was as if I were breathing in another memory, each breath out, giving another memory to her. My Mom taught me how to time travel when she had Alzheimer's, which ended up helping me survive her death. I trusted that I could give myself over to that journey through time with the surge of memories flowing through me.

Grief: Ontological Liminality

Grief is a cellular matter. [...] One lives a kind of cocoon existence: the world fades and the body shrinks into the space of its grieving.
– Robert Romanyshyn, 2002, p.55

Grief animates this project, which I began before my Mom died. In a way, this project is an anatomy of grief. A map of my grief for me to find myself in, because I spent so much time lost. Lost in the fog of confusion, right there with my Mom. The mother I knew was changing, becoming unrecognizable in some ways, long before her death. As I became a secondary

caregiver for my Mom, I grieved the parent-child relationship I was used to. I was privileged to grow up with a Mom I could rely on to take care of me. As her disease progressed, I lost the mom who could take care of me and gained a mom who I could take care of.

What is the grieving process like when losing someone to Alzheimer's? Although depression and stress in caregivers of people with Alzheimer's has been widely researched (Schulz et al., 2003), caregiver grief has gained relatively little focus (Large & Slinger, 2015). It has been suggested that caregiver grief has often been misdiagnosed as depression, especially the phenomenon of anticipatory grief (Walker & Pomeroy, 1996). Grief is a relational phenomenon. What is unique about grief associated with losing someone from Alzheimer's?

Anticipatory grief is a kind of grief that is experienced when anticipating losses. It is typically an experience that motivates discussions about dying and addressing any problems in interpersonal relationships with the person dying (Rando, 2000). When losing somebody to Alzheimer's, anticipatory grief is the anticipation of further decline and eventual death. Unlike with many other forms of illness, anticipatory grief in this context often occurs simultaneously with another form of grief: ambiguous loss.

Ambiguous loss refers to experiencing ambiguity of absence and presence, and is a defining experience among people who love somebody with Alzheimer's disease where the person is physically present but experiences profound psychosocial changes (Boss, 2009). Pauline Boss (2009) wrote, "Ambiguous loss is the most stressful loss people can face" (Boss, 2009, p. 20). Marwit and Meuser (2005) argued that the grief of caregivers of individuals with dementia is "more akin to true grief [post-death grief] than it is to the anticipatory grief experienced by caregivers of patients with other terminal illness" (p. 202). Ambiguous loss can cause people to feel bewildered and immobilized, as the uncertainty makes it difficult to adjust,

for example by reorganizing roles in the family system. Blandin and Pepin (2017) expanded on this by acknowledging the compounded serial losses with the progression of the disease. Furthermore, Boss articulated that “people are denied symbolic rituals that ordinarily support a clear loss” (2009, p. 7), resulting in an isolated and unvalidated experience for many people going through an ambiguous loss. Finally, because ambiguous losses typically last for an indefinite, ongoing period of time, it causes emotional exhaustion from the relentless uncertainty (Boss, 2009, pp. 7-8).

The experience of ambiguous loss has gained more focus in the literature than post-death grief in loved ones of somebody with Alzheimer’s disease due to its unique and defining nature. Caregivers experience a magnitude of stress preceding physical death considered equal to or greater than the stress in bereavement after physical death (Noyes et al., 2010). Ambiguous loss creates significant distress before the death of the loved one with Alzheimer’s, and because it is largely unrecognized and even stigmatized, it warrants the attention it has gotten in research. I aim to describe here a more in-depth account of the lived experience of ambiguous loss and the effect it has on post-death grief when losing a loved one to Alzheimer’s.

Liminality

Blandin and Pepin (2017) offer the concept of liminality to describe the experience of pre-death grief of a loved one with Alzheimer’s:

Liminality is the state of being in-between a previous situation and an emerging situation.

Liminal is derived from the Latin word *limen*, which means threshold. In crossing a threshold, there is movement from one place or state to another; when one stands in the threshold, however, one is betwixt and between both. (p. 73)

Liminality, or being-between-worlds, is a fruitful concept in delivering a more

phenomenological understanding of ambiguous grief.

This description resonates with my experience of grief before my Mom died. It felt as if the level of stress and grief I felt while my Mom was living with Alzheimer's had no place to go or be recognized. While life outside my family carried on with its usual high-speed clip, for the majority of the time my Mom had Alzheimer's she thought of me as still being a college student. I was in multiple timescapes simultaneously. Although I was young when she was sick – in my late 20s – I felt trapped in her perception as being in an earlier developmental stage, further complicating my family's ability to reorganize our roles. My social experience of time was either stuck too far in the past or moving too quickly toward the future to make room for the slow-moving elephant that was my grief. I was time-travelling every day, held between my grief and my obligations to my PhD program as a psychologist in training.

Liminality in the grief of loving someone with Alzheimer's touches identity, time, and community, and is a crucial concept in understanding what I experienced as a form of time traveling. Blandin and Pepin offer the concept of liminality to describe the ambiguous pre-death grief, because of the ongoing losses paired with ongoing presence of the person with Alzheimer's. However, I wish to expand this description of liminality beyond the feelings provoked by the ambiguous presence and absence of the person with Alzheimer's, or the ambiguous presence and absence after the death of someone with Alzheimer's. Liminality describes an ontological experience in this grief. Existential phenomenology can help form a deeper description of this.

From an existential phenomenological perspective, human existence cannot be separated from the world in which we dwell. "Dasein" is a term that the philosopher Martin Heidegger coined, which literally means "there-being," and is often understood as "presence" or as

“existence” (Heidegger, 1962). The importance of this term is that it refuses to disentangle being from its context, and captures the fact that people are permeable with their environment, histories, and relationships as “being-in-the-world.” Erik Craig describes being-in-the-world eloquently: “I don’t experience my existence as stopping here with my flesh but, rather, as extending outward, and outward, and outward, in space, time, and relation” (2008, p. 242). Being-in-the-world is a term that is hyphenated because it indicates the utterly inseparable nature of Being from the context within which one exists. In other words, not only do we not exist in a vacuum, we could not exist in a vacuum. Rather, we exist because of, and out in, the world.

Erik Craig provides a beautiful example of what this term can contribute to our understanding of grief:

If we do exist, fundamentally, as in-the-world, as-world, then others, especially significant others, actually comprise our existence, to a mighty degree are our existence. [...] When a person loses a parent, or child, or partner, or dear friend to death, it is a significant feature of that individual’s very own existence and identity within it that dies. (2008, p. 247)

Our in-the-world nature means that we inhabit *shared* lifeworlds with the people and other beings and places with whom we are in relation. When somebody who sculpts part of our lifeworld dies, our lifeworld itself is altered. The part of our lifeworld we shared with that other closes off. “This expansion and mutual overlap of selves may be regarded as the most essential presupposition of grief. For it means that the other is present for me both *as other*, as the real person, and as the “*other-of-myself*,” as part of my self-experience” (Fuchs, 2018, p. 49). Being in relationship entails an overlapping, a joining of lifeworlds. Our relational nature is not simply that we deeply love others and suffer when we lose them, but that we are, in fact, partially

constituted by others. This implies a deep relationality—an intercorporeality—a permeability with other beings. We are permeable not only to other beings, but also to places, things, cultures, and histories. Our skin is a permeable threshold, our being emanates beyond the periphery of the skin, and the world lives as much outside us as it does inside us.

Being-with others is something that takes place in time, and it is worth here exploring the role of temporality in grief. Intercorporeality with loved ones that I mentioned above also implies a “*contemporality*” with others: “from early childhood on, intersubjective synchronicity is constituted through the presence of others and through our shared reference to the world, as in joint attention or joint action” (Fuchs, 2018, p. 50). Pre-reflexive understanding of one’s location in time, or *lived time*, is in part constituted by being in relation to other beings in time. This is what Minkowski (1970, p. 65) refers to as “lived synchronism,” that is, a kind of vital contact with or harmonious immersion in the flow of the world around us. Loved ones constitute a large portion of our sense of being-in-the-world. This anchoring into contemporality with other beings begins in infancy, with the attunement between baby and caregiver through responsive touch, gaze, facial expressions and tone of voice (Wallin, 2007, p. 293). Anchoring into relationship with caregivers is also a way of anchoring into a rhythmic time that expands beyond the simple internal rhythms of breath and heartbeat.

Relationships with caregivers expand the horizon of lived time. The experience of time is deeply influenced by the relationship one has with one’s earliest attachment figures. Fuchs wrote, “present time, or the ‘now’, always means the actual, imagined or at least implicit presence of others with whom we, in principle at least, co-experience the world” (2018, p. 50). This endures throughout the lifespan, though perhaps in a decreasingly conscious manner. When primary attachment relationships end due to the death of the caregiver, a temporal chasm

emerges. One's immersion in the flow of time that is established in part through the presence, real and imagined, of the primary attachment figure meets a fork in the road: time, of course, continues flowing, but the horizon of the lifeworld extended by the primary attachment figure stops in its tracks. Fuchs continued: "The temporality of grief may be described as a separation of two forms of time, one flowing, one arrested, which become more and more desynchronized" (2018, p. 50).

Already a sort of time traveling happens inadvertently, between the ongoing flow of the present and this arrested past in which the loved one was still alive. It is not uncommon for people to describe early grief as if they are barely present in the ongoing flow of time; their bodies feel heavy, their thoughts sluggish and unable to make simple decisions. Their awareness and attunement are mostly elsewhere in time, in the past with their loved one. This kind of time travel is not graceful.

Although I, too, experienced this sluggishness, I believe my contemporality with a loved one who had Alzheimer's disease taught me how to time travel before my Mom's death. There were two major ways in which my Mom taught me to be comfortable with time travel before being thrown into the time travel inherent in grief. One, of course, was the time travel involved in attuning to and joining with her lifeworld, which involved significant and sometimes rapid time travel between different periods of time in her own life. Second was the flip-side of the same coin: the intermittent departure from the flow of my situatedness in the broader sociocultural here and now. Being-with her meant being-away from my immediate surrounds, disengaging from my own ground. My Mom taught me about liminality while she was alive, which made the liminal nature of grieving her death easier to navigate, almost literally. I did not resist being thrust into the liminal when she died because I felt oriented to the liminal already.

Mariana Ortega, a Latina feminist phenomenologist, wrote that “Heidegger discusses the importance of Dasein being a historical being that interprets itself in specific environments, but he does not describe or engage with those environments” (2016, p. 56). Ortega’s important contribution to phenomenology focuses on sociocultural situatedness, and her attention to the specificity of the “world” of being-in-the-world is helpful in understanding the liminality I became oriented within while my Mom had Alzheimer’s. Ortega describes the being in a multiplicity of particular histories, using the example of Gloria Anzaldúa’s *Borderlands/La Frontera* (1999), in which Anzaldúa describes the international borderlands between the U.S. and Mexico. Ortega documents the multiplicities and in-betweenness of living under multiple conflicting sociopolitical histories simultaneously. Ortega proposes an “in-between, multiplicitous selfhood,” which has a condition of “liminality” and involves inhabiting “more than one world” and travelling constantly across worlds (2016, pp. 64-65). Ortega offers an understanding that the *self* is transformed by being in more than one world, and that liminality is not just a condition *out there in the world*, but one that becomes fundamental to the experience of *being*.

Ortega (2016) wrote that Latina feminist phenomenology underscores the ontic—the material conditions of being human—focusing especially on the “particular power relations informing specific economic, cultural, and societal ‘theres’” (p. 53). Those particular power-laden “theres” into which we are thrown (the ‘da’ of dasein) are complex, and impact things like mood, language, how we move through space, how we conceive of and experience time, and other existentialia. She articulates this as an integration of the ontic and the ontological – being liminal is an ontological trait, but it appears because of the world-traveling of belonging in multiple worlds. Ortega’s integration of the ontic and the ontological is important to this

discussion of liminality in the grief of losing a loved one to Alzheimer's. It also offers an understanding where the material conditions of the Anthropocene influence the ontological conditions of being-in-the-world.

The fact that Western societies tend to conceive of time as linear and bereavement as a minor interruption in productivity creates resistance to the multiplicitous experience of time, one that is internalized by people acculturated in these ideas. Of course, there are power dynamics behind this which animate subjectivity during the Anthropocene: a linear understanding of time is important to the economic system of capitalism, and limiting the time and space in which grief can be experienced keeps the engines of capital churning and diminishes resistance to the economic powers that spread unprecedented destruction through the natural world. Much like I tell my clients who experience depression that psychic numbing is a blunt instrument, one that tends to numb not only pain but also joy, something similar can be said of grief. Having time and space to fall apart in grief, to time travel in grief, puts the many ungrieved griefs of the past into reach. When you really let yourself go into the river of grief, the losses of our contemporary world shaped in the Anthropocene can come into sharp relief as well. Becoming oriented in the liminality of chronic grief is an important skill for being and dying in the Anthropocene, one which our most forgetful elders are skilled in helping us learn.

Liminality therefore is not simply a metaphor to describe the ambiguous presence and absence of a dying loved one. Liminality is an ontological experience of the griever, one that stretches being-in-time such that one experiences not simply being in the present *or* the past, but being in the present *and* the past simultaneously; it is a multiplicitous selfhood. Simms explains: *“From the beginning, perception is never neutral but shot through with memory and desire: memory of past perceptions and desire for connecting the present with the past”* (2008, pp. 34,

italics in the original). When loving somebody with Alzheimer's, the time travel required to join with the person in their present understanding of reality builds a certain skill, fortitude, and even mastery, like learning to ride a bike, in being in multiple worlds.

It is not uncommon to hear of people feeling relieved when a loved one dies from Alzheimer's (Doka, 2004), because the painful ambiguous grief that can last for years, and finally that ambiguous grief becomes—well, not ambiguous anymore. In my own experience, I would describe this differently. Compared with other deaths I have experienced, I felt well prepared to be in the liminality of grief, and so there was an ease in the grief after my Mom died. Not to mention, there was a shift in the social recognition and support I gained in the immediate aftermath of my Mom's death, which allowed me to further let go into my grief without trying to stay grounded in the here-and-now. Navigating the torrent of memories surging through me in the weeks after my Mom died felt like something I was already skilled in doing, which meant I did not need to resist the powerfully disorienting process of my own time travel. I could just let the memories come; I could trust that journey. Indeed, I could take refuge in my memories of my Mom; I let myself feel the reality of those memories not as a past which was irrevocably severed from the present, but as a place I visited through time travel that was just as real as anything else. I didn't look at the memories from the outside, but rather entered into them fully. This was the gift my Mom gave me, what she taught me in her own time travel while she had Alzheimer's. Losing her made me want her comfort more than anyone else's, and I was able to really receive that comfort by entering into my memories of her as the here and now.

Chapter 8: Discussion

Through autoethnographic, phenomenological and critical theoretical methods, this dissertation elaborated my relational connection to my Mom in the context of our cultural situatedness. I used evocative vignettes to trace my memories of being with my Mom while she had Alzheimer's disease. I then analyzed each vignette to connect my experience with wider cultural, political and historical meanings and phenomena to understand how our relational connection was permeated by and situated within a broader context. Through each vignette and its connected analysis, themes and implications emerged that supported the primary question of this dissertation: what can people with Alzheimer's disease can teach us about being, forgetting, and dying in the Anthropocene, an era of deep, collective forgetfulness about our interconnectedness with human and non-human beings? This chapter will briefly summarize the findings and questions explored in this dissertation, implications of the findings, limitations of the project, and directions for further inquiry.

Summary of Findings

The basic research prompts of this project were “what was my relationship with my Mom like while she had Alzheimer's disease?” and “how was our experience situated in broader sociocultural and historical contexts?” These questions aimed to describe and elaborate on the phenomenon in order to better understand what happened, and to share my stories of being with my Mom as a narrative offering of the complexities and gifts of loving someone with Alzheimer's disease. These prompts generated the stories which became the data that I used to address my overarching research question, “what can people with Alzheimer's disease teach us about being, forgetting and dying in the Anthropocene, an era of deep, collective forgetfulness

about our interconnectedness with human and non-human beings?” This question aims to synthesize the answers to the previous questions and offer a more generalizable take away from my experiences. This question also intends to challenge dominant discourses around a deficit model of understanding Alzheimer’s disease by asking what wisdom people with Alzheimer’s disease can offer humanity in the face of our collective existential crisis related to climate change.

I told many stories in this dissertation. I shared my pain about Alzheimer’s disease being the elephant in the room as my Mom denied having it. I observed how objects of her lifeworld became things again, de-objectified as her cognition changed over the course of the disease. I shared unexpected gifts my Mom gave me, including introducing me to ancestors who I didn’t know were there. I described a shape-shifting landscape and how my Mom would self-locate based on her emotional stirrings and memories of belonging in other landscapes. I shared the dilemma my family faced as my Mom’s health went downhill, and questions emerged of how best to care for her on the spectrum between prolonging her life and using physician-assisted dying. Finally, I shared the story of when my Mom died, and the skills she gave me in time traveling, which became a refuge in my grief.

Each of these stories was followed by a section of critical analysis, which elicited themes and connected my stories to broader psychological, sociocultural and philosophical phenomena and ideas. I analyzed the role of denial in psychological and sociocultural contexts, drawing a connection with the denial we see about the era of the Anthropocene. I explored the phenomenology of things, and the animacy of the unobjectified world around us. I discussed co-existentiality and intersubjectivity as ontological dimensions of experience. I explored dwelling as a fundamental aspect of existence, and the specificity of place as an anchor in identity. I

examined physician assisted dying as an artifact of Western allopathic medicine and situated it within an ecological-developmental context of human experience. Finally, I explored the ontology of liminality as a defining framework for the experience of ambiguous grief in losing a loved one to Alzheimer's disease.

This project traveled in many directions and integrated theoretical perspectives from multiple disciplines. Thematic threads that persisted throughout the project included the examination of selfhood and the Western, and specifically American, cultural values that limit our understandings of selfhood as being especially defined by cognition. I advanced stories and arguments that see people with Alzheimer's disease as having an ongoing selfhood that continues to contribute important, unique, and unreplaceable perspectives to their communities. Another core theme was an examination of how our understandings of selfhood influence what we consider to be "care." I advanced arguments about co-existentiality and interdependence that expand the scope of care. Through this project, I contributed to the development of a more robust understanding of being in relation to loved ones who have Alzheimer's disease, to offer language to the experiences of intersubjectivity that can deeply alter our own perception of what it means to navigate death and life, remembering and forgetting, in a Western neoliberal cultural context.

The overarching goal of this dissertation was to explore what it was like to share a relational world with my Mom while she lived with Alzheimer's disease that is responsive to the sociopolitical and historical dynamics of living in the Anthropocene, and to articulate the unique perspectives my Mom's forgetfulness could offer about how to live in a deeply forgetful era. I wanted my readers to feel in their bodies the rhythms of remembering, the textures of lifeworlds and temporal horizons shuffling. I intended for my readers to question what they have forgotten, to feel their own lacunas of belonging, and to inch toward the portals of liminality we are invited

to enter by our forgetful elders.

Implications

Our treatment of people with Alzheimer's disease speaks of who and what we are, and so the tangled veil is truly a mirror.
– Steven Sabat (2001, p. 340).

This dissertation offers findings specific to my relationship with my Mom while she had Alzheimer's, as well as implications that are generalizable beyond her and I. Importantly this dissertation advanced an exploration about subjectivity that expands Western understandings of intersubjectivity and cognition, and locates subjectivity within particular cultural contexts and fields of embodiment that extend beyond the periphery of the skin. How our culture thinks about and treats people with Alzheimer's is of philosophical and political significance. It has the potential to reveal our culture's ontological values and how those values promote alienation from the earth, from things, and from each other, and how people with Alzheimer's can teach us another way of being woven into our collective lifeworld.

The question that I aim to address in the implications section is: What can our most forgetful elders teach us about being, forgetting and dying in the Anthropocene, an era of deep, collective forgetfulness about our interconnectedness with human and non-human beings? By synthesizing the previous chapters I aim in this section to attempt an answer, or at least a partial answer, to this question. This is a question about wisdom, about the specific perspective and knowledge that people with Alzheimer's have. It is a question that aims not only to find some real answers, but that by asking it is also intended to help my readers resist the pathology paradigm, which looks at people with Alzheimer's from a deficit perspective. I intend for this section to offer the wisdom that arose in the space between my Mom and I during her journey

with Alzheimer's. Wisdom, an offering of perspective gained from experience. Although these themes are not exhaustive, they are the ones that most resonated with me and which most directly related to the data gathered and analyzed in previous sections of this dissertation.

Denial is part of the journey, and it needs to be worked through.

Denial is a life-saving defense mechanism that helps protect us from catastrophic anxiety. Denial is about anticipating psychic annihilation. Climate chaos brought on by the Anthropocene can, and probably should, trigger catastrophic anxiety; it is, after all, an existential threat. Denial about climate chaos is commonplace. It is not just in politicians and oil tycoons, and your difficult uncle you only see at holiday dinners. Denial is in you. Denial is in me. Denial is a curious squirrel who keeps coming back for more, who has learned that there will continue to be more and more scraps to forage as we uncover ever more about the crisis of the Anthropocene. Denial is best handled with compassion, reflection, generous resonance, and loving curiosity about the underlying anxiety. Accountability is the goal, but to create movement with denial, attend to the affect rather than the thought content. Catastrophic anxiety is decreased when we don't feel alone in it. Lean into connection, offer connection, when you notice denial. It takes tremendous courage to look at the Anthropocene, and we can't do it alone. Getting into connection might itself require accountability, as the same systems that have created the Anthropocene—capitalism and colonialism—also have created systemic social injustices which create and maintain chronic disconnection. We have our work cut out for us.

Listen for the animacy of things and other beings.

There is a lot more animacy around us than we have been trained to perceive as people socialized in American culture, steeped as it is in economics of exchange value and consumerism. Objectifying things makes your life easier – you reduce the friction between your

intention and the world of things. Another way of saying friction is relation. There is again a chronic disconnection—a species loneliness—that comes from our reliance on objectification and, ironically, the culture we live in practically demands constant objectification in order to belong. Robin Wall Kimmerer described species loneliness as “a deep, unnamed sadness stemming from estrangement from the rest of Creation, from the loss of relationship. As our dominance of the world has grown, we have become more isolated, more lonely when we can no longer call out to our neighbors” (Kimmerer, 2013, p. 208). My Mom experienced a decline of the ability to objectify things; examples I gave in this dissertation included her use of utensils and her way of talking about the mountains. Although objectification is not inherently and unequivocally bad, taking a receptive, curious stance toward things allows you to perceive the animacy in them. When you see from your heart rather than your head, animacy is easier to perceive. Being with the animacy of things and other beings is being connected. Feeling this connection with other beings – human and other-than-human – is an essential starting place for developing the motivation and political will to steer us out of climate chaos.

You can call upon your ancestors for support and guidance.

Although the medical model would look at the common experience of people with Alzheimer’s disease feeling the presence of their deceased parents or other loved ones as a delusion, it looks very different if you remove the lens of the pathology paradigm. My Mom sought her parents’ support during an incredible transformation in her life, and they showed up for her in her lived experience. Phenomenologically, they were present. When I worked to stay close to both her and my own lived experience rather than wed to how I *thought* the world worked, I was surprised to encounter our ancestors as well, an experience I feel uncertain that I would have ever had without my Mom showing me the way. This was a transformational

moment in my own life. Finding my ancestors connected me for the first time with a felt sense of an ancestral lineage, with a personal history larger than my own, with a sense of family history extending much farther back in time than the two generations that preceded me who I actually got to meet. My web of connection, my felt sense of belonging in the world, expanded considerably as a result. My Mom showed me that you can call upon your ancestors for support and guidance.

Did you know that you can time travel?

Learning how to be with somebody with Alzheimer's requires learning how to become comfortable with time travel. Although it felt ontologically disorienting to time travel with someone who has Alzheimer's, it ultimately taught me that time travel opens up past experiences as places of refuge, which became a great comfort in my journey with grief after my Mom died. Time travelling opens up familiar places from the past within which one can feel a felt sense of being at home. Time travel also allows for a longer engagement with what has passed, which is an important prerequisite to processes of accountability, justice, and healing. This is something that psychotherapists will understand as our field has begun to prize the question of "what happened to you?" over the question "what is wrong with you?". Healing involves looking back in time. Time travel is a skill built upon resisting the collective flow of time; departing from the cultural norms of how we structure and organize time. Time travel can become a form of resistance to the forgetfulness of our era of capitalism, colonialism, consumerism and media cycle, which collectively forgets by moving too quickly and linearly into the future to dwell in the spiral of history. Slow down. Go back in time. Revisit what has passed. Enter into the past with your being.

Agency in death is difficult to discern.

The Western medical industrial complex has made possible a particular kind of agency in dying through physician assisted death, at least in limited parts of the world. Although great consideration and ongoing debate surrounds the legality of this type of death, our individualistic society, a result of the main drivers of the Anthropocene – namely capitalism and colonialism – has insufficiently addressed interdependence as it relates to agency in dying. Our most forgetful elders remind us of our interdependence and complicate considerations of consent and agency, especially regarding death. They also highlight that decisions to prolong life are as meaningful and complex as decisions to hasten death. Our most forgetful elders remind us about the fluidity and permeability of subjectivity, and as such they offer no quick solutions to understanding and advocating for agency in death.

Be a steward of chronic grief.

Loving somebody with Alzheimer’s disease is a lesson in holding and honoring chronic grief. Chronic grief is a characteristic response to ongoing losses, ambiguous losses, and slow-moving decline. Chronic grief is incredibly painful and can create a feeling of being-between-worlds, or being liminal. Tending to chronic grief intentionally is necessary to survival; chronic grief will make itself known in a million little ways, coming out sideways if it is ignored. How can you be a good steward of chronic grief? What I have learned is that the basic ingredients are: making containers of time and space for it in your daily and weekly life, seeking connection so you have people whose arms you can fall apart into, and engaging in ritual. None of these things will make chronic grief go away, but they will all support your survival of it.

Becoming oriented in chronic grief is an important skill for being and dying in the Anthropocene. Although climate catastrophe continues to move incredibly fast on a geologic

time scale, measured in human life what we are facing is a type of decline that will last through our lifetimes, through multiple generations. Good tending of our grief is an important antidote to denial, and it is important for transmitting the knowledge we have now to new generations. Even stories from my parents' generation illuminate the slow-moving losses we have faced; simple stories about how many fewer bugs there are on the windshield after long drives now than when my parents were children. These are the stories that let us know about the change that is taking place around us, difficult sometimes to perceive from the shortness of our own lives. Grief will come not only about the loss of life we navigate in the sixth mass extinction event now taking place (Ceballos et al., 2015), but also how we got here through colonial violence enacted on humans and non-humans (Mitchell, 2020). As a settler myself, socialized in a culture which values objectification, commodification, exchange value, linear time, and has used genocide, slavery, and environmental destruction and exploitation as its building blocks, I grieve my very culture. I grieve the way I was taught to be in the world. I lament that this is all normal to me. Grieving a chronic, ongoing loss takes fortitude, intention, support and time. Our most forgetful elders, each held in social webs of chronic grief, teach us that it is possible to continue engaging with the most heart-breaking parts of our lives. They train us in being adept at the liminality of chronic grief. And this training, this preparation for transition, this willingness to undergo the pain of transformation, is necessary as we face the existential threat of climate chaos brought about by the drivers of the Anthropocene. If we are to respond to this threat with any success, we must be willing to have our lives transform, we must engage in losses, we must endure grief, for generations. Grief will either see us through the social transformations we need to survive this threat, or it will serve us through our own ending. Grief is a practice, one our forgetful elders are expert at teaching us, and practicing grief is the greatest skill to develop as we live during

climate catastrophe.

Care is political.

People with Alzheimer's need progressively more help from others as the disease progresses. The amount of care needed can be staggering, especially for the smaller social networks that are typical in American society during late-stage capitalism. The shrinking of social networks can be attributed to trends of people moving to different regions for work in a globalized economy, as well as to continuing processes of urbanization and gentrification of working-class neighborhoods, which fragment local support networks. Smaller care networks mean fewer people share the task of caregiving for people with Alzheimer's disease, which can significantly impact caregiver physical and mental health as well as the quality of life for those living with Alzheimer's. This dissertation has focused on themes about the gifts that our most forgetful elders give us individually and collectively. This final subsection of the implications section focuses on how we care for them, and how our most forgetful elders' gifts must be reciprocated within a framework of collective care.

Eldercare in general is an oft ignored but urgent area of attention for social justice activists and scholars. The state of our systems of care for our elders is inadequate, to put it gently. We are now seeing a swelling of the old age population as the baby boomers enter their 70s, but there has been no matching growth of the services catering to the old. The care services that do exist have been globalized, such that a large amount of care-work has shifted to the shoulders of immigrant women, who Silvia Federici (2012) reminds us are often undocumented and are vulnerable to a great deal of abuse: long hours of work, no paid sick leave or other benefits, exposure to racist behavior and sexual assault without adequate legal protections (p. 117). Meanwhile, for families who cannot afford to hire caregivers, publicly funded nursing

homes are what some call the concentration camps of our day: in 2008, for example, the U.S. government reported that 94% of our nursing homes have documented histories of abuse, neglect, and violations of safety and health standards (Federici, 2012, p. 117). Political economists and governments portray provisions that workers have won for their sustenance in old age such as pensions and social security as an “economic time bomb” – unsustainable and inadequate (Federici, 2012, p. 116).

Looking at the dire situation of eldercare in the U.S., and in particular for people with Alzheimer’s disease who often need high levels of care, we are implored to reinvent our systems of care. This is a question of our collective values. It is my hope that this dissertation casts light upon the value that people with Alzheimer’s give to our communities and acts as motivation for my readers to engage seriously with the issue of how we care for them. It will not be an easy problem to solve and will involve demanding a governmental redistribution of wealth and investments to provide adequate care for our most forgetful elders.

Areas for Further Study

This dissertation offers broad findings in regard to being in relation to people with Alzheimer’s disease and contributes to humanistic and phenomenological accounts of the lived experience of the disease. In addition to having implications for how we care for people with Alzheimer’s disease and understand their ongoing contributions to society, this dissertation led to a number of areas for further study. This dissertation has used autoethnographic means to arrive at important themes, so the themes are based upon my own lived experience of being in relation to my Mom. This dissertation is therefore very specifically culturally situated not only in the United States but more specifically in the unique and largely privileged intersections of identity

in which my Mom and I are located with regards to race, class, gender, ability, and other facets of social identity. This dissertation suggests that further study would be fruitful to capture how loving somebody with Alzheimer's might be mediated by these intersections of identity and cultural locations by examining the lived experience of people who occupy different positions with regards to social privilege and oppression. For example, one of the questions I asked in this dissertation was whether people with Alzheimer's disease who have lived in a single geographical area for their whole lives would have similar experiences of locating themselves in different places, or whether this phenomenon reflected my Mom's class privilege of having the financial resources to move to different parts of the country during her lifetime. Another fruitful area of further study would be to ask the question of what our most forgetful elders can teach us about being, forgetting and dying in the Anthropocene – by interviewing people with Alzheimer's disease what their perspective on it is. There would likely be different answers than revealed in this project, and the question itself, which is aimed at challenging the stigma associated with Alzheimer's disease, may be therapeutic to the participants who may not have previously considered their ongoing contributions to society.

Practical Applications

This dissertation suggests a number of practical applications regarding loving and caring for somebody with Alzheimer's disease. There is a general consensus that person-centered care for people with Alzheimer's is recommended, meaning that caregivers are encouraged to go with the flow of the person with Alzheimer's description of their lifeworld. If they talk about being in another time or place, it is recommended that caregivers improvise and join with the person's lived experience. However, practically this is sometimes done in a detached or condescending

way, without genuine curiosity and attention to what the caregiver might learn from the experience. This dissertation suggests that there are important benefits to caregivers from the act of joining with their loved ones that can increase the caregiver's comfort with time travel, a supportive factor in the experience of grief.

Other practical applications include the ways that intersubjectivity and permeability of people to their place, relationships, and orientation to things, may influence how we structure sites and relationships of caregiving. While there has been interest and attention in some assisted living facilities to the architectural and interior design of such structures to facilitate feelings of comfort and familiarity, these design considerations are often in tension with economic feasibility and are typically reserved for those who have considerable wealth. This dissertation emphasizes the importance of place for supporting a sense of safety and belonging for our most forgetful elders, and demonstrates that this is an essential need rather than something that should be reserved for those with the most economic means.

This dissertation may also be practically useful for other people who love somebody with Alzheimer's disease to gain insight into their own and their loved one's experiences. One of the very challenging parts of being in the position of loving somebody with Alzheimer's disease is feeling alone and misunderstood by peers who have not had similar experiences. That was certainly a part of my own experience, which was perhaps amplified because of my young age when I went through this, mostly during my 20s. Even at Alzheimer's support groups specific to adult children of parents with early onset Alzheimer's disease, I found myself to be younger by over a decade than anybody else who attended. My sense of isolation made my grief more difficult to carry. Reading literature such as this dissertation, which values personal narrative as the primary source of data, may reduce other's experience of feeling alone and may offer insights

that help people find the gifts in their forgetful elder's new ways of being in the world.

Finally, it is my hope that this dissertation offers practical guidance for our society to listen to the unique wisdom that our most forgetful elders can share about being, forgetting and dying in the Anthropocene. As we navigate collective issues of denial, transformation, existential threat, and grief, our forgetful elders can help us orient to a disorienting world.

Limitations

Any research based on a single person's lived experience, including case studies and autoethnographies, has inherent limitations. While these types of studies offer a depth of qualitative data that provide valuable insight, it is inherently difficult to make general claims from them. This dissertation has attempted to connect my personal narrative with philosophical and theoretical chapters that extend the narrative into more generalizable ideas, however they are still limited in scope and undoubtedly hold bias from my own cultural situatedness as a white able-bodied queer woman with class privilege. Writing autoethnographically into the forgetfulness of the Anthropocene was inherently challenging as I attempted to write into my own inherited forgetfulness from this era, and write toward another way of being in the world that I do not yet fully know how to be. Furthermore, the Anthropocene is such a broad concept that it was difficult at times to differentiate whether some aspects of what I wrote about were characteristic of the Anthropocene, or perhaps of some smaller or more limited and specific cultural phenomenon.

Further limitations are specific to the lack of representation of my Mom's voice in this dissertation. While the dissertation was specifically focused on my own experiences, I would have liked to discuss with her some of the ideas, themes, and gifts that I described receiving from

her to see how she perceived these things. Because this project began when she was already in the late stage of the disease and the majority of this dissertation was written following her death, I did not have the opportunity to do this. This is a significant limitation in verifying the accuracy of my perception of her experience, which I tried to mitigate by emphasizing that the data I collected was based upon my experience. It is also a limitation in my personal experience of this project: I wish I could have shared this with her for the sake of our connection and relationship. Although I don't know whether she would agree with everything that I wrote (in fact, knowing my Mom, I am fairly confident she would have opinions about a lot of the things I wrote!), I do know that she would be proud of my work and my ongoing dedication to our relationship. When she had Alzheimer's, she thought of me as younger than I was, and typically thought I was in college rather than in a PhD program. I know she would be profoundly proud of my decision to pursue a PhD in clinical psychology, and of course, the completion of this dissertation indicates my completion of my doctoral degree, which she would have been thrilled to celebrate.

Closing

This dissertation explored my lived experience of being in relation to my Mom and connected this experience with broader sociocultural, psychological, and philosophical phenomena and ideas. Above all, this project kept me deeply engaged in relationship with my Mom in all parts of my being – heart, head, body, spirit. She has offered me many gifts through her time with Alzheimer's disease, many of which will serve me as I continue to navigate being, forgetting and dying in the Anthropocene. Undoubtedly these gifts have and will continue to be expressed through me in my clinical work with patients, and I hope that this dissertation additionally extends her gifts to a wider audience. I also hope that it invites my readers to

become newly curious about relating to the forgetful elders in their lives, and to themselves should they become a forgetful elder in the future themselves, as we navigate the Anthropocene together.

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