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Ontologies of Dementia: Changing Forms of Selfhood, Personhood, and Temporality from the Relational Perspective of Caregivers

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Ontologies of Dementia: Changing Forms of Selfhood, Personhood, and Temporality from the Relational Perspective of Caregivers

Senior Project Submitted to
The Division of Social Studies
of Bard College

by
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Annandale-on-Hudson, New York
May 2022

For 麻麻 and 婆婆,
my grandmothers
(Lam Suk-Yin and Tsang [Kelly] Kit-Jan)

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Preface

I grew up spending my summers in Hong Kong, visiting both my parent's respective families. Memories of these visits are saturated by sensations of humid and hot weather, glacially air conditioned malls, the savory tang of snacks from the corner store, and feeling sleepy after long meals with my grandmothers. I have few recollections of my grandmothers before they began to exhibit signs of dementia, and so I had little frame of reference for what they were like prior to the onset of their cognitive decline. I remember my father's mother - known by me as *maa maa* (麻麻, *maa4 maa4*[1]) - as not particularly affectionate. Nonetheless, she showed me her love by accompanying me in watching Japanese cartoons dubbed over in Cantonese, or by putting food in my bowl during mealtimes. My mother's mother on the other hand, my *po po* (婆婆, *po4 po4*), was doting. She wore bob-cut style wigs, and frequently gave me candy and other tasty things. But by the time I was roughly ten, they had both begun to lose their memories and capability to care for themselves.

The rate of decline and forms of care were different for the both of them. One was gone four years after onset, the other passed away within the next two years. The two of them were given vastly different kinds of care. While my *maa maa* was wealthier, and could afford home care given to her by two Filipino migrant laborers, my *po po* did not have as much financial capital, and was placed into a nursing home. I stayed with *maa maa* in her luxury apartment, continued to watch television with her, and accompanied her to her favorite restaurants alongside my parents. At the same time, I would spend time with *po po* in the nursing home, simply sitting

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[1] The numbers represent the tonal pronunciation of each syllable in Cantonese using the jyutping romanization system. The number 4 here represents the fourth tone out of six.

there while my grandfather and parents fed her spoonfuls of whatever meal was being served that day at the facility.

Even as these slow days of caregiving accumulated, time was passing by quickly for me. I grew up to talk faster, spitting thoughts that spun my own understanding of the world and my experiences together into more complex ideas. Simultaneously, my grandmothers began to speak in simpler sentences, unable to find the right words they wanted or the right order in which to place their words. I went to school to learn about history and mathematics, and my grandmothers began to forget their children's names, to forget where and when they were in the world.

The emotional impact of the juxtaposition of my and my grandmothers' development was an incomprehensible puzzle to me as a child. Not understanding what was going on with my *maa maa* and *po po*, I was a petulant child during those summers. I would sulk and stubbornly refuse to talk to my grandmothers, partly because I didn't have the vocabulary to communicate what I was feeling with them, partly because I didn't understand why I had to spend all my time sitting around in their company doing nothing meaningful that I could discern. The result of this is that I missed much of my grandmothers' bids for my attention, or their acknowledgement of my presence. It wasn't until they had both died that I began to look back on my experiences, and realized the little markers of affection in their gestures.

This project is partially an apology: an apology for my ignorance and surliness towards my grandmothers as a grade schooler. I would also like to think of this project as an attempt to make sense of those summers I spent with my grandmothers - though it might be more of a reminder of the moments that were rife with meaning that I didn't comprehend until I was older. It is for the time that my *maa maa* entered my room at four in the morning during her nighttime wander around the apartment, where we conversed in a haze between sleep and waking through facial expressions and fragments of verbal language. It is for the trips to the nursing home, where I would sit by *po po's* bedside to exchange unspoken meaning through our gazes and the gestural mediation of my grandfather. Maybe significance is only imbued in these incidents upon my retrospective contemplation, but I would like to think that these occasions can be indicative of something other than a culmination of actions to make a scene.

I would also like to acknowledge that mortality, aging, and these illnesses that might come along with it, are understood in a myriad of ways. Not everyone's experience of caregiving for relatives with Alzheimer's disease or dementia is the same, and of course there are many economic, political, and cultural differences that will affect one's experience. Although I cannot deny that the questions asked are heavily informed by my own experiences, I hope that what is shown in this project might reflect some of the reader's own experiences. Through conducting six interviews with caregivers of people with either Alzhimer's disease or general dementia, I was able to gain perspectives on how others might experience these illnesses, even if they were not the ones with the condition. The interview questions have been included as supplemental material in Appendix B in order to provide an example of how my research was executed. What follows is an analytic examination of Alzheimer's and dementia in contexts of caregiving, selfhood, and temporality.

Introduction

It is 7 p.m. in Hong Kong, the standard time for dinner when he arrives at the door. "Oh, you're home from school already?" asks the 96 year old matriarch of the family to her youngest and 52 year old son. She glances up with squinted eyes from her rice bowl at her son who has stepped through the doorway of her apartment after a year of being absent. He has just arrived home from Boston to take care of his mother in Hong Kong for the summer, bringing with him his wife and child. The youngest son wearily puts down his luggage at his feet, and answers "Hi Mom. I'm home." He's glad to see his mother again, but he also knows that this summer she won't be the same.

The eldest son, 65 years old, pokes his head out of his bedroom, and comes out into the hallway to greet his younger brother. As the eldest son enters the shared living space, his mother turns to him and greets him by his father's name. "Our son is home," she states, referring to her eldest as her husband, and treating her youngest as if he were still a small child. With that, she promptly turns back to her favorite meal of steamed fish. The eldest son sighs in response. Walking up to his brother's family, he helps them move their luggage into the two bedrooms where they will be staying.

As the youngest son's family settles into their home for the summer, the eldest brother pulls the younger aside, murmuring, "She's gotten worse. I took her to the doctor last week but she has another appointment tomorrow. Remember to watch what she eats. I have to go now, my flight's at 10." With that, the eldest son picks up his own set of bags, and exits the apartment, leaving his mother in the care of his younger brother.

In families with a relative that has either Alzheimer's disease or dementia, it is not uncommon for the relative with the diagnosis to mistake their friends and family as someone else. This personal vignette is but one example of how the individual with Alzheimer's or dementia may display themselves to their loved ones. They are the same person their loved ones have always known, and yet they have also undeniably changed in who they are to us, as they no longer recognize their family and friends. They may not even behave or act as they did before the onset of their condition. These individuals represent to us an enigma of what it means to shift from one state of mental awareness to another. Embedded in this alteration of being are questions of what it means to be ill, what it means to have selfhood and personhood, and what it means to step out of a collective shared time.

Throughout this project, I will address the intertwining and overlapping conundrums of care, selfhood, personhood, and temporality within the conceptual structure (i.e., ontology) of Alzheimer's disease and dementia in three chapters. Using ethnographic interviews conducted with six caregivers of individuals with Alzheimer's disease or dementia,[2] I will represent and interpret narratives of how the diagnosis and lived experience of dementia conditions (as it relates to the aforementioned themes) affects not only the afflicted individuals, but also those around them. I will argue that interpersonal relationships in dementia conditions as perceived by the caregivers are changed when retrospective memories of the individual with the illness are inconsistent with their present self. It is my hope that this project and what follows it will present a rethinking of the relationships between caregivers and persons with dementia, as well as reexamining the stigmas surrounding diseases of aging.

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[2] It should be noted that all caregivers interviewed resided in North America at the time of our conversation, but that the people they cared for at the time of their caregiving did not always live in North America. One individual with dementia was located in Lithuania at the time, and another was in Northern China.

In order to situate the interlocutors in this ethnography, Chapter 1 will introduce perspectives of dementia and the experiences of relatives and caregivers in supporting those with dementia conditions. While stigma surrounding older adults exists partly because they are separated from other adults in terms of autonomy, and their abilities monitored for deficits (Kaufman 1994), illnesses [3] of aging such as Alzheimer's disease and dementia contribute to the concept of age-related deterioration. These connotations surrounding illnesses of aging can have an impact on the relationships of those with a dementia condition, as their symptoms may require a caregiver to look out for their wellbeing. The forms that caregiving can take, as well as the motivation in caring, can also make it comforting or distressing for both the caregiver and the care recipient (Anngela-Cole & Busch 2011; Kaufman 1994; Kim et al. 2015). This can change the meanings found in the relative's or caregiver's relationship with the person with dementia from their relationship prior to the condition's onset, as the addition of illness changes their interpersonal dynamics. The ramifications of dementia symptoms might then call into question who the individual with the condition is in terms of identity, and this can potentially stigmatize their selfhood (Degnen 2005; Diekfuss et al. 2018; Kontos 2010).

Chapter 2 will address the complexities of selfhood and personhood, as well as descriptions of the changes or consistencies perceived in the individual with Alzheimer's prior to and after the onset of the disease as expressed by their caregivers. Selfhood and personhood as used in this project will be defined in this chapter, but for now, a simple definition of selfhood[4] is that this encompasses personality and behavior, whereas personhood is the state of living as human, that is, the capacity to have the right to be perceived as human. Memory, and its

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[3] The term used here in this context to refer to states of worsened physical and mental health.

[4] It ought to be noted that the definition of selfhood is a widely contested subject (Herskovits, 1995), but for the purposes of this project a single working definition will be utilized.

importance to sense of self and interpersonal relationships will also be examined in conjunction with the formation of selfhood as perceived by another. The label of illness and disease in dementia conditions will also be explored where it intersects personhood. In repositioning the integrity of these concepts to dementia, I will suggest new frameworks of looking at self and personhood in dementia, such as through embodied selfhood (Kontos 2010) and moral agency. As this chapter looks at memory in constructing the individual, time must also be discussed as it relates to the idea of memories as past recollection.

Weaving together theories of time, the caregivers' presence in time, and their observations of the care recipient's perceived time, Chapter 3 will explore temporality as it relates to selfhood in Alzheimer's disease and dementia. In this project, temporality is utilized and interpreted as an individual's existence in, and relationship with time. Time is intrinsic to people's understanding of memory and agency (which may be a key component of selfhood in North American contexts), as this concept helps people to comprehend how actions or intervals of moments are relevant to their social experiences (Greenhouse 1996). Furthermore, individuals do not necessarily experience time collectively, and Orona's (2002) work on caregivers and Alzheimer's patients depicts how present, or current, time is not similarly experienced. Whereas the care recipients appeared to the caregivers to be in a state of time interpreted as the caregivers' past, caregivers themselves felt that they were living in the present. Time was discrepant between caregiver and care recipient, and as such, they did not share the same experience of time. Caregivers' and care recipients' perception of themselves and the events they observe in their frame of time, or observe in referencing their memories, directly affects their sense of identity. Thus, this project seeks to understand selfhood as it is intertwined with memory and temporality.

The prevalence of Alzheimer's and dementia only continues to grow as the United States' population's life expectancy increases, making the implications of these illnesses more salient and relevant to understand. As of 2020, it was estimated that 5.8 million Americans who were 65 years of age or older had Alzheimer's disease, and it was even cited by the Centers for Disease Control and Prevention (CDC) as the sixth leading cause of death in the United States (CDC 2020). This placement of Alzheimer's among the top ten causes of death in the U.S., along with the disease's connotations of leading to a loss of self agency and identity, only add to the stigma of senility or helplessness that surrounds those with cognitive decline. How, though, do definitions of dementia as a disease affect ideas about older adulthood? What does the dialectical relationship of the caregiver and care recipient suggest about selfhood? And what happens when memory becomes conflated with personal identity? These questions do not have a summarized answer, and to begin to comprehend these questions requires a contextualized approach to dementia. It is by situating the nature and being of care, self/personhood, and temporality's position in dementia, that this project can then explain the effect dementia has on their ontology.

An Overview of the Neurobiology, and Symptomatology of Alzheimer's Disease

Current knowledge and research in Alzheimer's disease points to the condition as being a cause of dementia, which is a psychological disorder associated with issues in memory and cognition. The classic symptoms of Alzheimer's include memory loss that interferes with daily functioning, trouble completing activities of daily living (e.g., feeding and dressing oneself, taking transportation), impaired thinking and judgment, as well as changes in normal mood and behavior (CDC 2020; NIA 2021). The National Institute on Aging (NIA) lists individuals 65 years of age and older as the most at risk of the condition (2021). However, despite Alzheimer's disease most often being diagnosed in individuals 65 years of age or older, many cases of this condition have also been reported in younger adults (such instances being diagnosed as early onset Alzheimer's disease in one's forties or fifties), implying that the disease is not solely one of aging.

The cause of Alzheimer's disease is thought to be due to the misfolding and accumulation of the normally soluble proteins amyloid-beta and tau (Mrdjen et al. 2019). In a literature review of the neurobiology of Alzheimer's disease, Mrdjen et al. (2019) propose that the most common theory of how this occurs is thought to be through the excess accumulation of the precursor for the protein amyloid-beta, which leads to its increased levels in the brain, causing extracellular plaques. This increase in amyloid-beta then sets of a chain of events in which the protein tau becomes hyperphosphorylated (i.e., the over attachment of a phosphate group to the protein), leading to the creation of neurofibrillary tangles (NFTs). Figure 1 depicts the physical appearance of these plaques and NFTs in a slice of the brain.

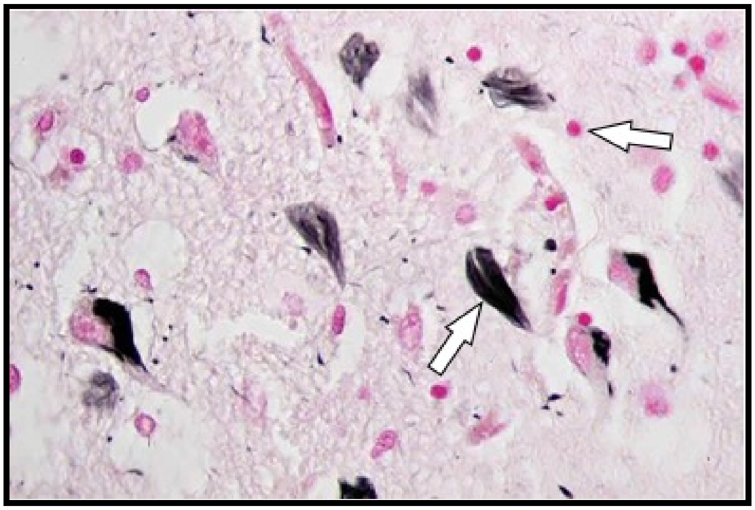

Figure 1 - Image of Amyloid Plaques (arrow on far right) and
Neurofibrillary Tangles (arrow on left)
Source: https://www.alzheimers.org.uk/

These plaques and NFTs can lead to synaptic loss, reduced brain blood flow, neurovascular dysfunction, and neuronal cell death. Mrjden et al. (2019) note that the synaptic loss in the neocortex and limbic system of the brain is best correlated with disease's symptoms of cognitive impairment and amnesia. They also add that the presence of NFTs correlates well with brain atrophy in the later stages of Alzheimer's, providing further evidence for the neurodegenerative basis of the disease.

While this model of Alzheimer's disease contributes evidence for the progression of the condition neurologically, this in itself does not explain why it has grown to be synonymous with cognitive decline. Though the symptoms of Alzheimer's may include cognitive impairment and memory loss, these manifestations of the disease do not themselves clarify the broader connotations of the disease that imply a loss of self and disconnection with the linear flow of time. These symptoms only tell us of the behavioral aspects of the disease, but not of how they are associated with, and interact with the diagnosed individual and their relationship with others. Nor do these symptoms provide a reasoning as to why the disease is synonymous with that of geriatric illness and the deterioration of identity.

The Origins of the Alzheimer's Disease Diagnosis

The earliest mention of dementia in Europe dates back to 500 BCE, where a Greek lawmaker revised inheritance laws to allow for the designation of nonfamilial beneficiaries, so long as they were not impaired by old age (Fox 1989). However, the term of dementia did not come into usage until the first century CE, when a Roman writer coined the term, and described the condition of old age as a situation in which dementia occurred (Fox 1989). The historian Robert Fox (1989) documents the rise of the diagnosis and term of ‘senile dementia’ through the 16th, 17th, and 18th centuries, and by the 19th century, older adults had been fully separated from the broader categorization of adulthood. This distinction formed out of the advances of medicine at the time, as the cell degeneration theory of senescence became widely accepted. As such, “because of an inability to explain or deter this cell degeneration, the clinical characterization of the entire stage of senescence began to be viewed as a medical problem” (Fox 1989, 61). Dementia began to be perceived as an incurable disease, and along with it, all other mental illnesses that were found among the elderly.

By the twentieth century, psychiatry began to reconceptualize dementia, creating new frameworks for treatment and differentiating Alzheimer’s disease as a cause of dementia, rather than a dementia itself. Although Dr. Alois Alzheimer (a German psychiatrist) had documented the first case of the disease in 1906, it was not until the 1960s that the study of dementia and Alzheimer’s disease began to gain traction (Ballenger 2000; Fox 1989). This was because of the popularization of the theory that Alzheimer’s was a socially produced illness (that is, through the societal marginalization of the elderly), meaning that it could therefore be treated through mentally therapeutic interventions (Ballenger 2000). Yet it was not until the 1980s that Alzheimer’s fully gained its status as a disease, when medical studies conducted and confirmed a pathological neural basis for the condition (Katzman & Bick 2000). This categorization of disease allowed it to be distinguished from other forms of dementia, and thus, with the support of caregivers who had been impacted both emotionally and financially in supporting the afflicted individual, an interest and urgency was generated for its study (Fox 1989; Katzman & Bick 2000).

Currently, diagnosis of Alzheimer's disease cannot be fully determined until autopsy upon death, but clinical behavioral criteria and brain scans have been utilized in order to determine whether the person has dementia, and with less certainty, what kind of dementia they have (Gaugler et al. 2013). In a meta-analysis by Gaugler and colleagues (2013), it was found that Alzheimer's disease diagnosis from cerebrospinal fluid (CSF) levels of the proteins tau and amyloid-beta could potentially supplement that of clinical diagnosis. In early stages of Alzheimer's, high levels of CSF tau and low levels of CSF amyloid could lead to earlier diagnosis, thus giving the individual more time to get their personal affairs in order before they are deemed incapable of making informed decisions. A few studies included in the meta-analysis had also concluded that fludeoxyglucose positron emission tomography (FDG PET) scans were more accurate in diagnosing Alzheimer's than clinical criteria. With this uncertainty in diagnosis, it remains difficult to classify diagnosed individuals as either carriers of disease or afflicted with cognitive decline. The implications of this uncertainty can be the demarcation of the ill as in a near-death state, in contrast to the healthy living (Kleinman 2020).

Though history can begin to speak to the marginalization of older adults given the past associations of diminished abilities and incurable mental illnesses in this age group, the questions surrounding loss of identity and temporal dissonance associated with Alzheimer's disease remain. Moreover, the implications of the pathological label onto the condition do more than designate it as an illness, as the label brings with it its own stigmas. Given these lingering queries, research into these persisting concepts is needed to comprehend the scope of what it means to live with Alzheimer's, both for those afflicted with it and for their caregivers.

Methodology: Ethnography

Within the entirety of this project, I have used the qualitative research method of ethnography in order to provide descriptively rich examples of those with Alzheimer's disease or dementia, as well as their caregivers. I interviewed six caregivers and family members of those who know or knew of individuals with Alzheimer's disease or dementia (see Appendix A for a list of interlocutors). These interviews were semi-structured, meaning that there were some set questions that were asked of every participant, but that additional questions were also asked to elicit elaboration on certain subjects, depending on what the participant detailed during the discussion. Examples of set discussion questions were "Can you tell me about any changes you have noticed in the individual with dementia or Alzheimer's since the onset of the illness?" and "In your experience, how do you think the individual with dementia or Alzheimer's perceives time?" (see Appendix B for a full list of questions). The interviews took place over video conferencing platforms (e.g. Zoom) and in-person, in order to accommodate the comfort levels of each interlocutor during the ongoing (as of 2021-2022) COVID-19 pandemic.

Ethnographic research is used in order to provide a narrative from the perspective of the interlocutors. Similarly to Kontos' (2010) ethnography on embodied selfhood in Alzheimer's, I will be presenting and then using anthropological theory to interpret an interlocutor's experiences and views. Each vignette interlocutors included will be intended to show and elaborate on the meanings expressed in their own words, body language, and social context. Some of the quotes from our interviews may not contain perfect grammar or clarity, but I have decided to preserve the language spoken so as not to proverbially put words in their mouth.[5] Additionally, this has the effect of demonstrating the rhythm of each interlocutor's speech pattern.

Before proceeding through the rest of this senior project, I want to acknowledge the limitations of this project in using caregiver perspectives to describe and extend to individuals with Alzheimer's disease and dementia. As no individuals diagnosed were allowed to be interviewed,[6] the language and ideas expressed by their caregivers may obscure the thoughts and perspectives of the diagnosed individuals. This may have the effect of, to borrow from Trouillot (1995), 'silencing the past,' or in this case, those narratives that were unable to be told by the witnesses themselves. Rather, the stories and themes included in this ethnography come from second hand experiences and accounts. The caregiver has greater power to shape the ideas expressed and recorded, than the individual with dementia, and as such, the person determined to have full cognitive capacity becomes the authority on the subject of the illness experienced by their care recipient. Taking into account these power dynamics at play, this project seeks to highlight the positionality of the individuals as those of family, caregivers, and social workers for those with dementia. The purpose behind this project and using these research methods is not to necessarily create a generalizable theory applicable to all those with Alzheimer's and dementia, but rather to highlight the shared experiences and complexities of care, selfhood, personhood, and temporality.

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[5] Although all interviews were conducted in English, some of the interlocutors' first language was not English.

[6] As per the request of the Bard College Institutional Review Board.

Chapter 1: Dementia and Caregiving

Through the actions and sentiments of caregivers and relatives, an abstract picture begins to emerge of how dementia informs the specific forms of care that is brought to the person with the condition. The framework of dementia as an illness can orient caregivers as to what they feel is most important in the care recipient's wellbeing, and it can also provide a lens through which to look at the transformed meanings and emotions in their relationships. By understanding this perspective of dementia from the other (i.e., the view from the person without dementia), it may help us to contextualize the tender ways in which care informs the caregiver of their relationship with the care recipient.

The Blurred Boundary between Normal Aging and Dementia

When I ask Donna, a former college counselor who was also the primary caregiver for her mother, what she thinks Alzheimer's disease is, she pauses to gather her thoughts. She thinks deeply on the question I have posed before answering, "It takes away all of your ability to care for yourself or make decisions for yourself, to even understand who you are anymore." Her voice comes through steadily over the Zoom call, and she carries herself with assurance. She explains that, "You lose all sense of your pride," as the disease progresses. Although I can only see her from her shoulders upward, her expression conveys the gravity and solemnity of the effects of Alzheimer's on her mother to me. In the early stages of her mother's Alzheimer's, Donna had attributed her lapses in memory to the normal process of aging and growing old. Yet, as her mother began to lose a day's worth of memories, Donna began to have misgivings about the nature of her mother's forgetfulness. After her mother was formally diagnosed with Alzheimer's, she began to notice her mother's growing inability to dress and feed herself. Using these declining cognitive abilities and behaviors as indications of the disease's effects, her impression of Alzheimer's became that of a disease that induced loss of dignity by the growing inability of being able to take care of oneself.

The sense that Alzheimer's disease and dementia brings about a loss of autonomy or agency is not uncommon among caregivers (Herskovits 1995; Orona 2002). As they witness their care recipient become unable to remember to turn off the stove, take their medication, and forget their names, they can often be struck by the feeling that their relative is no longer the person they once were. This is also often accompanied by frustration and stress, as they struggle to take care of that individual's needs. The shift in perception of the cognitively declined person as different after the onset of the dementia condition is gradual. All of the caregivers had expressed to me that the first signs of dementia, which were often described as forgetting the errands that had been run or yesterday's events, had appeared to be *normal* aging (that is, normal in the sense of expected consequences of aging) to them. Often, it was not until a routine doctor's visit or until the symptoms (e.g., slow processing of, or inability to understand language) had progressed to the point where it could no longer be attributed to what they considered to be normal. In response to my questions as to how they defined Alzheimer's disease and dementia in contrast to normal aging, three of the interlocutors in this project stressed a loss of selfhood in these conditions, in contrast to normal aging in which this sense of identity could be retained. The first warning signs of dementia, especially that of memory loss, thus became a precursor to signs of a disease causing deterioration of the self upon retrospection. The symptoms become transformed from those of aging to that of illness.

However, the difference between dementia and old age is not so clear cut as to the former being defined by the dissipation of self and personhood, and the latter its retention. The distinction between dementia from normal old age is one that grounds itself not in symptomatology, but instead in that of physical change. Historically, there has been difficulty distinguishing between development and aging, and even what is considered typical and atypical in theories of aging (Schroots 1996). Thus, psychological theorists of aging usually defer to the neurobiological explanations that have arisen in recent years to differentiate normal old age from pathological old age (Trevisan et al. 2019). While such neurobiological explanations for Alzheimer's disease have been demonstrated (Katzman & Bick 2002; Mrdjen et al. 2019), these elucidations do not apply to other dementias that do not have a clear physical cause. This leaves dementia, (when applied as a general term for cognitive decline) in a state of limbo between old age and pathological aging, as neither aging theorists nor neurologists can identify the specifics of how dementia sets itself apart from normal development.

Given the ongoing debate on the parameters of the definition of normal aging, this raises the question of how exactly the categorization of dementia as an illness has cemented itself. When Donna characterized Alzheimer's with the observed behavioral abnormalities of dementia as displayed by her mother, her form of description suggests that the disease is marked by its social implications, rather than its biological effects. Gilman (1988) suggests that illnesses are socially constructed on the basis of specific ideological needs and structured along the categories of representation accepted within that ideology. Consequently, considering the U.S. context, it might be posited that the dementia illness category was created because of the need to demarcate old age as different from normal aging in order to make dementia a treatable illness. This is not to say that all dementias are not pathological, but that because dementia is synonymous with old aging, yet also has no clear foundational cause, this particular characterization adds to the stigma surrounding older adulthood.

The dementia illness label may provide some comfort for the friends and family of those with this dementia, as it provides an explanation and a word to explain their perceived anomalous behavior, and subdue the fear of loss of control, making aging for U.S. older adults manageable (Herskovits 1995). Once diagnosed with dementia or Alzheimer's, that is to say, an illness, it marks the individual as different, as an other,[7] and "once applied to a person, spoils radically that individual's identity and is not easily removed" (Kleinman 2020, 20). In early stages of dementia, this diagnosis can serve to strip the individual of agency and the competency to make their own informed decisions (Herskovits 1995). Thus, it is important to note that such a diagnosis should not immediately equate to the diagnosed individual's loss of agency.

Despite the implications of the dementia and Alzheimer's disease categorization having the potential to rob a person of agency, it can also provide an explanation for what is happening to them, therefore functioning as a double-edged sword. Anne, a social worker who had been involved with cases with older adults, and whose own mother had had dementia, repeatedly stressed that early diagnosis was important so that these older adults could keep their autonomy to some extent. She noted that preparations for later symptoms and eventual death (e.g., making a living will, filing a 'Do Not Resuscitate' form) should be undertaken in the early stages so that these older adults may "keep their independence, but [...] know that they have people watching out for them." Receiving early diagnosis allowed the diagnosed individual to plan ahead for the

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[7] To clarify, the use of 'other' here is defined as someone who has departed from ordinary conventions, or behaviors; alienated.

future care that they might need while maintaining their autonomy. Personal safety and security could be found in the dementia diagnosis, allowing others to keep an eye on the future care recipient. The obtaining of an early diagnosis can then further give solace and greater stability for the individual with the condition, in that it provides them with the opportunity to have an explanation of the trajectory they might undergo in the illness. Rather than having an absence of reason as to why they were becoming more forgetful (as was the case for interlocutor's relative/care recipient), they could find reassurance in having an idea of what was causing their memory detriment. As such, the dementia diagnosis does not strictly have the ability to strip agency from the diagnosed, but also impart some mental reassurance in giving them the knowledge of their condition and ability to plan ahead for its progression.

Forms of Care in Alzheimer's and Other Dementias

With the diagnosis of Alzheimer's disease and/or dementia, comes the task of holistic personal care (i.e., care involving everyday physical and mental wellbeing). Each individual has their own set of circumstances and support networks, and as such, there is no set standard of care for the person with these conditions. I ask Anne about whether there is any criteria as to when the person with Alzheimer's might need to be placed into a care facility, or need in-home assistance, but she tells me that it varies from individual to individual. The Zoom call shows that her glasses glint in the fluorescent lights of her room, giving her the look of a scattered but incredibly sharp woman, as she rapidly lists off the factors involved in assessing what kind of assistance the individual with Alzheimer's and/or dementia might need. She says that the opinions of the doctor, social worker, and family (if the person has relatives) must all sit down to figure out what is to be done. Additionally, whether or not the person has health insurance or a supportive community must be factored into the discussion in order to determine what is in the realm of possibility for care.

The aspects of care planning considered in U.S. healthcare systems emphasizes physical health and mitigation of physical risk, rather than mental wellbeing. Kaufman (1994) writes that, “In U.S. geriatrics, old people who do not exhibit complete functional autonomy, who cannot care for all their own needs independently, who have functional limitations, are thought to embody risk. The task of the practitioner is to specify the nature and extent of that risk - as disease - so it can be contained and diminished” (443). This is evident in Anne’s rundown of consultants and factors in her care-support assessment of older adults. She focused on what could be done to ensure that the older adult took their medication, how to prevent the possibility of physical injury, as well as how to keep track of their whereabouts so that they would not wander off. Emotional problems that arose among her clients were talked about in terms of how to manage the outburst of distress, and how to minimize the harm to that individual and others. Ensuring the physical safety and health of the client was emphasized over their social support network, showing that decreasing the risk that they posed to themselves and others was the primary concern for Anne’s practice of social work with the elderly. It is not that reducing risk to older adults is unimportant, but emotional comfort may be overlooked in favor of physical comfort in such professions.

Although the mitigation of risk is the main duty for healthcare professionals, some familial caregivers tend to view care more holistically. They are not only concerned with the person’s physical health, but they also think about ways in which to keep them in emotional comfort or happiness. Karl, an undergraduate student from China, whose grandmother had Alzheimer's disease, spends most of our conversation describing what he would do to keep his grandmother happy. His presence is calmer and more grounded than when we usually spend time together,[8] and his voice is soft as he reminisces on his grandmother's emotional state,

> ...if she is in a good mood, like when she's happier, it's pretty telling that it almost makes things easier because at that point she doesn't really recognize a lot of the people around her. [...] But in the last lucid times, she felt kind of lonely, because last conversation she had Alzheimer's, she invited me to sleep over, next to her, but in the same bed, so she wanted the company...

Karl's remarks allude towards how keeping the person with Alzheimer's happy also eases the emotional strain involved in caregiving for the family. He also mentioned her loneliness, and when he finishes speaking, he grows quiet. It is clear that that last conversation has made a deep impression on him. His time spent with his grandmother during her days with Alzheimer's are marked by him simply keeping her company by watching television programs with her, as well as by feeding her her favorite snacks (despite them being bad for her health because of her diabetes). Although her physical health was not inconsequential in Karl's care practice, it mattered less than his grandmother's ability to enjoy life while she still could. He cared a lot for her emotional wellbeing, and he seemed to be a little sad as he recalled these moments. For Karl, his grandmother's happiness took precedence over her physical health, a value which stands in contrast to healthcare professionals' concerns.

In the process of determining how to care for the person with dementia and/or Alzheimer's disease, an array of possibilities are presented, ranging from care facilities to in-home forms of care, whether that involves hiring outside help or sourcing from within the

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[8] In the interest of practicing reflexivity, I should mention that Karl is a good friend of mine. His usual disposition is one that is full of energy, and he is always ready to spontaneously jump into action.

family. Interestingly, among the caregivers I talked to, care support was determined not by the individual with dementia, but rather by their families once they deemed that the individual no longer had the ability to make informed decisions. This implies that the individual is often not consulted as to what they may want as support, or what they think is best for themselves. Yet, it should be noted that by the time of their diagnosis, many of my interlocutors said that the care recipient often was not aware of the progression of their symptoms. As such, the caregivers took matters into their own hands and assumed the responsibility of making decisions concerning their wellbeing. Some of the caregivers expressed that if their relative had been more aware of their condition, they might have discussed with them what they wanted in terms of care. Regardless, the non-consultation with the care recipient once they have passed a certain threshold of self awareness of their symptoms as determined by the caregiver marks a point of social exclusion (Taylor 2008). The exclusion from the decision making process delineates the boundary between persons with exercisable agency and those who have lost that right. As Kleinman (2020) and Taylor (2008) have previously observed, the indication of illness separates the person from other adults. Once ascribed with severe illness that impedes judgment, the person with the dementia condition can no longer have the capacity to be agential because of their impaired cognizance.[9]

With enough wealth, some caregivers might decide to place the individual with Alzheimer's disease into a care facility. This was the case for Donna's mother, as the family felt that this would be a viable solution to keep an eye on her when they were away in order to ensure that no harm came to her. Her children all had jobs that did not allow them to take extended time

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[9] I am hesitant to extrapolate further on the processes of deciding on forms of caregiving, as care recipients' personal perspectives are absent from my research. Though the care recipients have been made incapable of agency by the categorization of a mentally incapacitating illness, it should be noted that they are not necessarily treated without respect.

off to care for their mother during the day, and as such a care facility where she could be looked after around the clock had seemed like the best option. The particular facility that this family had chosen specialized in care for older adults with memory deficits. Furthermore, it was also nearby Donna's home, and so this enabled her to regularly visit her mother so she could check in with her. Yet, Donna had some serious concerns and reservations about the facility. Throughout the interview, she stressed that the facility was poorly managed, and negligent to the individual needs of its residents. There had been a few occasions where she had visited her mother, only to find out that she had not been bathed in a few days, or that she had taken a fall that had left a bruise on her arm. "People that work there need better guidance and training," she sighed. She expressed that the staff had never contacted her outside of the facility, and that this was a source of both frustration and worry, as she felt that she should immediately be notified if any issues arose. For Donna, the care facility had become a much needed resource for the health of her mother, yet simultaneously, it posed a source of potential danger because of its inattentive staff. On the other hand, Karl and his family had had the opportunity to take care of his grandmother using home care workers and caring for the grandmother themselves. At the very early stages of Karl's grandmother's Alzheimer's disease, she had been able to reside in her own home, with some help of a hired home care worker. As her disease progressed, and she began to wander outside of the home without knowing how to return, the family made the decision to move her in with Karl's uncle and aunt, who were both retired at the time. They were able to look after his grandmother nearly every day, providing her meals, and keeping an eye out on her wandering. Despite the familial care, Karl says that this did not mitigate his grandmother's loneliness as his uncle and aunt were still busy with various everyday tasks and errands. She often asked for company, and recognizing the weight of the request, Karl obliged. For Karl, this allowed him to feel closer and appreciate the time left with his grandmother.

Caregiver Motivations, Meanings, and Burdens

The circumstances, and thus the forms of care given to the individual with dementia and Alzheimer's disease vary greatly, but the relationships that bind the caregiver with the care recipient are fraught with tension. Motivations or reasons for caregiving can have an impact on the level of caregiver burden (i.e., emotional distress felt by the caregiver), as well as the caregiver's ability to cope with challenges (Anngela-Cole & Busch 2011; Kim et al. 2015). A caregiver may have intrinsic (e.g., spending time with loved ones or self-fulfillment as a motivation for caregiving) and extrinsic motivations (e.g., monetary gain or familial obligation conflicting with self desires), but those who demonstrate more intrinsic motivation have better long term quality of life and spirituality than those who cite more extrinsic motivation (Kim et al. 2015). Furthermore, those who cite more extrinsic motivation may have greater difficulty coping with challenges that arise during caregiving (Ng et al. 2016). In particular, extrinsic filial piety (i.e., obligation to family) which is when the value is engaged in to please others and not voluntarily by oneself, can exacerbate caregiver burden (Ng et al. 2016).[10] In this project, the caregivers interviewed largely displayed intrinsic motivation in caregiving, citing love for the care recipient and a desire to give support to family in a time of need.

For Emma, a musician and piano teacher with Indonesian heritage, caregiving for her mother was driven by a desire to repay her mother for the love devoted to raising her. She

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[10] Conversely, when filial piety is intrinsic, it does not have the adverse effects associated with its extrinsically oriented counterpart.

described her mother as her best friend, and upon the first occasion that her mother had forgotten Emma's relationship to her as her daughter, she began to contemplate their past shared relationship. Speaking softly with grounded composure, she described the process it took for her to reconcile the hurt of no longer being recognized with her desire to give care:

> I basically grieved for a year and a half, for the onset. But after that, I slowly realize, like what should I do? What are the things I can do to help her, knowing that my best friend is no longer here, my mother is no longer here, it's the time for me to really take care of her, you know- what she has done in the past? How she has been, how to say… sacrificing a lot for me and my brother? Like, it's time for me to pay back, basically. So that was what I had in mind. So after that, things becomes better, things become lighter.

After taking the time to understand her emotions and changing relationship, Emma's motivation as a caregiver became one of intrinsic motivation rooted in filial piety. Her dedication and obligation to family was a positive value; one that she volitionally engaged in in order to repay her mother for the care given to her as a child. She took care of her mother because she was grateful for her mother's time, and appreciated the effort it took to raise her. This positive motivation benefited Emma's mental wellbeing, as the strain caused by the initial work of caregiving was eased by her desire to give back to her mother. In line with previous work by Kim and colleagues (2015), her intrinsically based motivation may have granted her better quality of life than if she had had extrinsic motivations. Changing her feelings led to a shift in her relationship to her mother, indicating that the emotional affect behind caregiving contains the potential to reorganize the meanings found in personal relationships.

This process of caregiving serves to strengthen bonds, as well as imbue new meanings into relationships between the caregiver and care recipient, shifting the representation of power and memory by retrospection. Jacob, an architect whose family had immigrated to Canada from

Lithuania, was called upon by his grandfather to help him take care of his grandmother, shortly after he had finished college. With graying hair that he routinely brushes out of his eyes, his tone of voice is gentle but melancholy, as he remembers the six months he spent caregiving. He recalled that as a child, his grandparents had been watching over him and his siblings, but now that he was older, the roles had been reversed. Jacob remembered how strange it felt, to watch over his grandmother, preventing her from falling, and making sure that she did not rearrange the furniture, as was her habit. When she entered the hospital due to her declining physical health, he thinks back to his practices of care, "As I recall she either, I don't know if she had fevers… it was also summer, it just seemed like a lot of times I needed to have a cold towel and just be like, wiping her brow, but it was like, just providing calmness? A little bit of touch, speaking to her, trying to be reassuring..." The caring process for his grandmother adjusted his senses so that they extended to her and beyond his own self, as it required of him that he understood the discomfort of sweat from the heat of the summer. This practice of sensory care sustains the personhood of the elderly with cognitive decline "by incorporating the sensory aspects of elders' histories into their own bodily practice, making each client's sensorium a part of their own embodied engagements with the world" (Buch 2013, 642). Taking the sensory world beyond that of just physicality, Jacob also comprehended that his words might not reach her given her state of cognitive decline, and utilized touch as a medium to communicate. Touch thus extended the sensory world to encompass that of emotion, and as such, by using his capacity to empathize and her sense of touch, he provided comfort by using physical closeness. As such, although his grandmother may no longer exhibit the same ability to communicate, he maintained his relationship with his grandmother through meanings conveyed in touch.

The act of caregiving also allowed Jacob to strengthen and incorporate new meanings into his and his grandfather's relationship. As Jacob grew closer with his grandfather, the two of them began to bond over the shared task of caring: "At the time I think it could've been for memories and kind of like, extend the bond with my grandfather? Because you know, we were still fully… he was still healthy enough that we could have conversations and what I was doing was helping him help her, and helping her but it was really because he was still present." Jacob had not only the experience caring for his grandmother with dementia, but also witnessed his grandfather's grief at his wife's declining health. Caring for his grandmother was a form of showing his love for her, yet it also had the effect of deepening his relationship with his grandfather. The practice of caring for another with his grandfather shifted the dynamics of his family, where the responsibility they felt for his grandmother pulled them closer together. The shared experience of caregiving expanded their familial context, in which they had to agree upon and acknowledge the decision-making power they held over his grandmother. The changing power dynamics between him and his grandparents thus allowed him to refashion his previous memories in order to incorporate his new understanding of what his grandparents were to him, and how he was positioned to them. His competence was raised above that of his grandmother, and now as a young adult, he was an equal to his grandfather. Caregiving was a meaningful and tender process that promoted his relationship growth through shared experiences and shifting familial dynamics.

In other situations, the process of caregiving can also result in the emotional strain on the caregiver, and how the individual deals with this can have an effect on the care recipient. The memory loss, physical disabilities, loss of participating in family events, and lack of respite that often accompanies caring for someone with dementia can cause frustration and constant worry in the caregiver (Anngela-Cole & Busch 2011). These stressors and the anticipatory grief of the death of the individual with dementia can lead to issues arising in care, as the caregiver becomes exhausted and less emotionally available for the care recipient. As a social worker and her mother's primary caregiver, Anne's experiences allowed her to reflect on the depths of a relationship and the social boundaries that are set depending on the type of connection to the individual with dementia. Her voice becomes constricted with concern, as she reenacts the irritation and anxiety she experienced in caregiving for her mother,

> But at the same time, we sense a helplessness, because she cannot change. But when you do the same thing repeatedly, you get so tired, stressed, frustrated. So sometimes we can lose our temper and say that, "You already asked me!" but after that, you know that she doesn't know, that she cannot help it, and so we have our internal struggle, even though, yes, on one hand we understand and sympathize. But on one hand we are real frustrated, but we cannot change [...] sometimes you cannot help it, your frustration.

As she recalls her experience, she stresses the syllables of her words into fraught bites of tension. The repetition of instruction from Anne coupled with her mother's inability to remember recent events caused Anne to feel distressed. Although she knew that it was not her mother's fault for being unable to retain the information, she wrestled with the weight of her emotions and the explanation for her mother's behavior. The frustration that welled up was tied to the care for her mother, as she was anxious at the prospect of the possibility of her mother wandering away from home and being unable to find her way back again. The buildup of the stress and worry from these incidents, and the intensity of the concerns of the caregiver can thus result in what is known as caregiver burden.

Caregiver burden can be lessened by family support, respite, spirituality (Anngela-Cole & Busch 2011), but may be experienced differently depending on the type of relationship, potentially blurring boundaries between the caregiver and care recipient. Family support can be both a source of support and stress, with less discomfort with intrinsic motivation or more with extrinsic motivation (Ng et al. 2016), and spirituality during caregiving can lead to long-term peace and meaning in life (Kim et al. 2015). Additionally, Anne emphasized the importance of respite and boundaries for caregivers, and contrasted her own experiences with her mother with that of her relationship with her clients. With her mother, she felt she needed to be watchful of her mother at all times. She needed to be able to respond to her mother's calls late at night, and be responsible for her wellbeing even if she was away from home. On the other hand, she had clear boundaries and expectations from her clients, where she was only expected to work the standard nine to five workday. If she received a call in the middle of the night from her clients, she would wait until the next morning to return their call. If there was an emergency, she would call emergency services, but she would not be held responsible for what came after that. This relationship and set of boundaries with her clients allowed her to rest from caring, and as such, she was able to cope with the challenges that came up during her job. Though respite was easier to achieve with the clients, Anne's example of the differentiated boundaries and spaces between the clients and her mother illustrates the importance of respite in caregiving. While Anne was able to separate herself from her clients, her mother had become an extension of her routine concerns. The felt obligation to ensure her mother's wellbeing blurred the setting of priorities for herself and her mother, resulting in caregiver burden, but she was able to maintain these borders between herself and her clients, and as such, was able to keep her mental health intact.

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Conceptualizing Alzheimer's disease and dementia as illness sets the basis from which practices of caregiving for those with these markers is then formed, but threading through these perspectives and performances, are shifted expressions of personhood and self, as mediated through the various manifestations of care and caregivers. By marking the persons with dementia as incurably ill, the label marks a form of social exclusion and departure from normalcy, thus creating a different version of personhood. In supporting people with such a diagnosis, caregivers, often family, step in to make decisions for the person with dementia once they are perceived to be incapable of making informed decisions. This action shifts the center of agential power from the individual with dementia to the caregiver. The experience of cognitive decline may be primarily felt by the diagnosed person, but the sensations and performances of selfhood are extended to the caregiver. Such extensions of the self can be found in touch and empathy from the caregiver's perspective. Meaning and reproduction of the caregiver's and care recipient's relationship are found in every interaction. As such, Alzheimer's disease and dementia require a restructuring of what it means to have selfhood, especially a conception of identity that moves beyond the boundaries of memory.

Chapter 2: Representations of Selfhood and Personhood

The conditions of dementia and Alzheimer’s disease are those that confront both the individual and their caregiver with what it means to have a self or be a person. Throughout the process of supporting the older adult with these conditions, caregivers might begin to wonder what it is like to no longer be able to bathe oneself, or play a game of chess, or even to struggle to remember the names of family members. Such thoughts might prompt one to examine what their agency means to themselves, and what aspects of themselves make up their identity. When faced with a relative or dear friend with steadily worsening memory, the other without the condition loses what seems to be the only marker of their shared experience. It might seem as if one can no longer recognize that person. But does this truly mean that they are not the same person one once knew? What follows in this chapter is a demonstration of selfhood and personhood that both extend beyond unimpaired cognizance and are influenced by retrospective memory.

The Impact of The Label ‘Illnesses of Aging’ on Selfhood and Personhood

Common definitions of selfhood from North Americans might incorporate abstractions of personality, individuality, and the possession of agency, but views of identity in terms of self do not always include these notions, nor do they always construct identity in the same manner. For instance, some Andeans in Peru may not separate their own being, their selves, from the land they inhabit, and sacred natural formations such as mountains may be seen as extensions of themselves (de la Cadena 2010). Other conceptions of self may draw on interpersonal interactions, and refuse fixed, stagnant interpretations. In Buddhist teachings, the self is impermanent, constantly changing, and is sometimes interpreted as a non-self, or *anatta*

(Cassaniti 2015). In thinking of temporality and self, the anthropologist Catherine Degnen theorized that "Self-formation is not a uniform nor necessarily chronological process [...] but rather is experienced as a cyclical, multistranded web of relations. Senses of self vary depending on who they are being performed for, and the self is forged in a dialectical relationship with others'" (Degnen 2010, 51). Degnen's definition of selfhood offers a perspective that exemplifies the fluidity of the individual, but only scratches the surface of what it might be to see the selfhood of another from an outsider perspective. As seen, there are diverse conceptions of selfhood, and given the many various transnational backgrounds of my interlocutors, this chapter cannot address all of their different formations of self. Therefore this chapter will utilize the North American description of selfhood - as this North American context is shared with all my participants - and will define selfhood as the amalgamation of behaviors, experiences, emotions, and personality traits.

Following Annette Liebing's (2006) example[11] and use of the philosopher Giorgio Agamben (1988) in her research on dementia, I will similarly define personhood as the state of living as human (that is, the capacity to have the right to be perceived as human, as opposed to a simple life form). Alzheimer's disease and dementia affect the concept of personhood through its association with illness, the ramifications of which may leave the afflicted individual in a state of 'life devoid of value' (Agamben 1988). Drawing from Ancient Greek philosophy, Agamben (1988) notes that Greek terminology had no singular term for life, but rather, life as a concept was divided into two terms: *zoe*, referring to the condition of living common to all living things, and *bios*, indicating the proper form or way of living to individuals and groups. While initially

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[11] And following her leading note that Agamben (1988) has been widely influential and popularized in recent social studies literature.

Greek legal and political society was only concerned with *bios*, the later incorporation of *zoe* into documents such as various declarations of human rights made life political. The inclusion of *zoe* allowed for a distinction to be made between sacred life (i.e., purposeful and valued life) and bare life (i.e., life devoid of value). Alzheimer's and dementia, by their associations with loss of agency and personality, then transforms an individual from a state of sacred life, to a state of bare life (Liebing 2006).

The label of illness in dementia and its association with gerontology involves "conflict between 'our' contempt for 'weak elderly,' who violate Protestant and capitalist work ethic values" (Herskovits 1995, 151), and as such, these individuals take on bare life, a social death, because of their perceived incapacity to lead a purposeful and valuable life. Older adults and those with cognitive decline might not be able to work long hours or engage in heavy physical labor, therefore slowing down production and labor which work against the demands of the capitalist work ethic. Similarly, principles of Protestant work ethic such as diligence and discipline might be transgressed in the process of aging because of older adults' potential incapability to keep track of multiple tasks. This violation of capitalist and Protestant work ethic by older adults and those with dementia conditions is consequently a 'social death' that may take place before the 'biological death' (Liebing 2006).

The process of this social death, as facilitated by the onset of dementia, has its basis in memory impairment (loss of memory or amnesia) and recognition. This conflation of identity and memory is seen in the sentiments expressed by Karl. Similarly to Donna who expressed that Alzheimer's disease entailed a loss of agency, he believed that "it's almost like, it's kind of like your body is still there and aging as it is, but that part of you - that part of your past is just slowly dying away, it’s like your soul is just deteriorating, and snippets of your experience, it just- it just no longer exists [...] it’s really horrifying for me.” After seeing what his grandmother had experienced, Karl was fearful of the possibility that he himself might eventually have Alzheimer’s. He also demonstrated a serious concern at the possibility of the disease being hereditary, and his voice grew quieter as he imagined what would happen if his mother were to develop the disease. For Karl, lived experiences preserved through memory were the most valuable aspect of his self and personhood. The thought of losing his memories evoked a language of decay, as he described the disease as something that caused ‘death’ and ‘deterioration’ of past and soul.

The use of these words by Karl elicit a strong suggestion of memory as synonymous with one’s individuality, and this notion has ramifications on interpersonal relationships. If amnesia due to dementia or Alzheimer’s indicates a social death (Liebing 2006), it may also include the death of the self or the soul. When death of the self is through memory loss, relationships to individuals who are seen to have no self become harder to maintain in the same manner as before the onset of dementia. These interpersonal ties to the individual with dementia or Alzheimer’s are thus seen as one sided, in that they are only recognized by the person with memories of the relationship. A social connection that is reciprocated by the individual with these illnesses becomes impossible if their identity is perceived to have disintegrated along with their memory. Yet, meanings between those with a dementia condition and their caregivers can both remain and change, as discussed in Chapter 1. The people with such illnesses continue to live and interact with others, though they may no longer be as socially aware as they once were.

The conflation of amnesia in dementia with identity loss can be traced back to its representation as an illness of old age. Notably, amnesia caused by factors other than aging is often represented as a product of injury, and is not associated with a loss of self. However, when it is associated with old age as a symptom of disease, it is transformed into this fear of selfhood death. This particular connection of memory loss and disease is an ontological insecurity, as it disrupts the notion of a 'whole' and 'healthy' mind or sense of self (Gilman 1988). It prompts the unafflicted (healthy) person to make a distinction between their *whole* self, and the afflicted (diseased, ill) individual's *fractured* self, in order to resolve this ontological insecurity by denying one's own sense of fragility (Gilman 1988).

Memory is not the sole marker of personal identity. Evidence from a psychological study on perceived identity change in frontotemporal dementia and Alzheimer's disease patients by Strohminger and Nichols (2015) has indicated that neither amnesia nor emotional change in these illnesses led to identity change. Rather, it was only a change in moral traits that significantly predicted identity change. Though memory is an aspect of personhood that may be held most important to one's own self concept,[12] selfhood is apparent in the individual in a myriad of ways. These other aspects of selfhood may include emotional demeanor and behavioral mannerisms among others, and some of these aspects of self remain even in Alzheimer's disease and dementia.

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[12] Memory loss in dementia and Alzheimer's disease does typically involve deficits in episodic memory (i.e., those pertaining to personal events) and semantic memory (i.e., conceptual or factual knowledge), but procedural memory (i.e., the ability to learn behaviors that operate at the unconscious/automatic level) remains relatively intact compared to other types of memory (Gold & Budson, 2008).

Extensions of The Self Beyond Memory

Despite some definitions of Alzheimer's disease and dementia from my interlocutors containing sentiments that the illnesses were a loss of selfhood, all of the stories they had to tell were rich in fond descriptions of identity in the person with the illness. Although identity was not explicitly apparent in the sense that the individuals were fully lucid (or self aware), the individuals typically displayed some sort of recognition toward the caregiver. This recognition may not be grounded in retrievable memory, but this recognition remained in a state of *knowing*. This knowing recognition was founded on feelings of familiarity in contrast to specifically recalling something in recognition. For example, Donna, recalling a visit with her mother after a period of absence, had mentioned that her mother had recognized her, but that "she didn't understand our relationship anymore." Her mother had continued to greet her brightly, though she may not have been able to remember Donna's name. What remained in the reciprocity of Donna and her mother's relationship was not what could be construed as a definable relationship status, but what could be called familiarity. The characteristic personality that made up her mother's self to Donna remained, and that aspect of selfhood was sustained throughout her mother's various social networks (Taylor 2008). Therefore, individuals with cognitive decline (including Donna's mother) are able to distribute and impart aspects of themselves unto others through intimate interactions. As such, those selves that they display to others in interpersonal relationships do not disappear with memory loss.

It is also of note that a diminished lack of self-awareness is not indicative of a loss of selfhood or identity. Conditions such as anosognosia (i.e., impaired self-awareness; the inability to recognize one's own mental impairment) in those with Alzheimer's disease may seem to suggest diminished selfhood in being unaware of one's own current mental state (Maki et al. 2012; Zamboni et al. 2012), but this in itself only means that their self perception has become discrepant with the conception of themselves from the non-cognitively impaired. While a study by Maki et al. (2012) showed that perception of mood and behavior was significantly between the person with Alzheimer's and their caregiver, they also found that caregivers gave higher severity assessments of mood and behavior than the Alzheimer's patients in the moderate Alzheimer's condition. Although this may be further indication of the severity of anosognosia, looked at from a different perspective, it might also suggest that the caregiver views the patient to be in a worse condition than is actually being experienced by the patient. It implies that in anosognosia, people no longer have a grasp or accurate assessment of their embodied current emotional state (though it may be true that they can no longer grasp the extent of their cognitive abilities), but this does not reflect the intensity of feeling that is felt by that individual. As such, this condition does not imply a diminished ability to feel, and it is this remaining ability to feel that can unveil sites of embodied selfhood.

Bodies can also become positions of selfhood through corporeal behavior that can be exercised at low levels of consciousness and without reproduction of verbal language (Kontos 2010). These expressions of embodied selfhood can be found in personal preferences, creativity, social etiquette, care, and facial and gestural communication (Kontos 2010). Such facets of embodied selfhood are often not found to be reduced in states of cognitive decline, including dementia and Alzheimer's disease. These markers were often present in descriptions of characteristics that remained in the afflicted individual even after the onset of the disease, and were displayed with the same intensity or frequency as before the onset.

Among displays of personal preferences as embodied selfhood, taste preference was one that was described to me by half of my interlocutors. In a moment of fondness, Karl recalls that his grandmother had a sweet tooth. Though his grandmother had diabetes and this meant that too much sugar would be detrimental to her physical health, he also recalled the happiness that each sweet treat would bring her:

> She loves this particular kind of cake, just let her have it. She is very happy when she get to have some of that. [...] I mean, coming from China, it has changed so much in the past years, and if she is still living in the memory of when resources weren't as like, accessible as it is now, then having those treats would be a scarce opportunity [...] Everytime she has this, it's like the first time she's having it.

Using the historical background of China's periods of food scarcity[13] to contextualize her love of cake, Karl describes exactly how this taste preference has remained in his grandmother. She may not remember who her grandson is, or what year it might be, but her recognition of sweetness remains through her taste sensorium.[14] Karl told me that she had displayed a pattern of craving sweet things, even if she could not remember the specific kind of cake that she liked. Given that this particular preference for sweet things remained displayed in her bodily faculties, and that this appreciation was not diminished in the progression of her Alzheimer's disease, a marker of personal identity has remained in her body. Her retrievable memory of that specific cake is not needed to be indicative of who she is. Her grandson attributed a part of her selfhood, her being, to her personal taste preferences.

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[13] Though Karl did not mention a specific historical period, it might be inferred from context, as his grandmother should have been a young child or adult around the time of the Great Chinese Famine in 1958.

[14] Notably, Alzheimer's disease does not affect procedural memory relative to other memory types as much (Gold & Budson, 2008), and this might suggest that memories that operate at lower levels of awareness might be better retained, and have a higher likelihood of successful retrieval.

Other instances of embodied selfhood include the use of facial and gestural communication (Kontos 2010), and this is seen in Emma's rich description of her mother's use of her body and emulation of sound to convey meaning. Scrunching up her face to match her mother's face when she had lost control of her bowels, Emma imitates the way her mother uses her body to communicate with her when language has been forgotten. There is humor and slight embarrassment in Emma's voice when she describes this particular incident of discomfort, "Um, just last night, she farted and she was like 'Oh, I fart?' [laughing, she blows a raspberry to recreate the entirety of her mother's response]. She was actually making that sound, and I was like, 'Oh, okay!' She was actually able to express that!" Though her mother might not have the language capabilities she once had, the emulation of the sounds of actions or things still remained within her faculty. Her mother's ability to make connections with others did not vanish upon the onset of her dementia, but instead, she made use of other forms of communication that might be overlooked in the presence of more complex language. With her unique patterns of speech and facial features, she retained a full set of embodied methods that she could use to relay meanings. Selfhood was therefore not limited to her ability to use structured and grammatically correct language.

In addition to these observations of body and sound as alternative forms of communication of selfhood, I also found that tone of voice could convey meaning, regardless of the actual words spoken. While Emma did recount instances in which her mother utilized facial expressions to convey her intentions or emotions, the pitch and cadence of voice was also used between them to bring greater meaning into their interactions. Though Emma and her mother usually use Indonesian to communicate, Emma switched to Singlish (a dialect of English used in

Singapore) to illustrate to me how she modulated her voice to indicate her intentions, “So I will say in Indonesian, ‘We’re going to change your pants, yeah?’ so that kind of like really, I guess how to say, it’s peaceful, reassuring…” Her example question is spoken softly, with no hard pronunciation of either vowels or consonants in order to reach a reassuring note. The ‘yeah’ in this sentence ends in a rising tone, where her pitch is higher than at the beginning of her sentence to impart a questioning ring. Emma then switches cadence to model a response her mother might make, “...and she will respond, ‘Oh, yeah…’” The ‘oh’ is pronounced with a similar rising intonation of the first ‘yeah,’ but it is softer and more subdued. In contrast to Emma’s first ‘yeah,’ her imitation of her mother’s yeah is drawn out, and is spoken at a lower pitch, but combined with the ‘oh’ at the beginning, it gives the entirety of the short phrase an affirmative tone. The response might overall not seem to be rife with a consenting inclination, but the tone of voice added to the two simple words is able to transform the syllables into one imbued with meaning relevant to the self.

It is unclear as to whether this specific instance of meaning conveyed in this tone of voice can be conveyed in other languages, but it is clear that the presence of selfhood is not diminished in the absence of higher cognitive functions. Other indicators of selfhood remain in the individuals with dementia, especially as displayed through the body and voice. Yet the way in which Alzheimer’s disease and dementia confront others without these conditions with what self and personhood is, is most readily apparent in the ways in which personhood is performed in appearances of spirituality and morality.

Morality and Personhood

The bestowing of personhood involves the recognition of moral identity (e.g., a self with social values), an identity which is made up of agential status (Higgs & Gilleard 2016). In dementia conditions, personhood can be disrupted when moral identity is perceived to be relinquished through cognitive decline. When the individual with cognitive impairment is thought to be incapable of making decisions for themselves and exhibit memory loss, their personhood may be seen to have decayed in their illness. They become fragments of their selves, as the unifying force of continuity that is memory is incapacitated (Gilman 1988; Higgs & Gilleard 2016), and are perceived to be unable to make moral value judgements or maintain self-consciousness in order to be an agent (Higgs & Gilleard 2016).

The retaining of morality with agential status in conditions of cognitive decline might be due to its similarity to implicit memory (i.e., memories that do not require conscious recollection).[15] Moral values play a key role in social etiquette, as these are the concepts that are relied upon in order to meet the criteria of social acceptability by being polite and behaving in a respectable manner (e.g., saying thank you after someone does something for you requires the knowledge to assess the action as a social nicety). As social etiquette is something that can be performed reflexively without much conscious thought, it might be suggested that morality is housed in procedural implicit memory. In contrast to forms of declarative memory (i.e., memory devoted to the conscious recollection of factual information), procedural memory, a subcategory of implicit memory, is memory involving skills or behaviors that can be performed at an unconscious or automatic level. Even in Alzheimer's disease, procedural memory remains

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[15] Approached from a psychological standpoint, memory can be divided into two types: declarative (explicit), and implicit memory. These two types can then be further divided into further sub-categories, such as semantic, episodic, procedural etc., but these other forms of memory are beyond the scope of this paper.

relatively more intact and less diminished in comparison to forms of declarative memory (Gold & Budson 2008). It may then stand to reason that with morality being involved in the performance of social etiquette (such as making value judgements), and social etiquette being a skill that can be recalled unconsciously, moral identity's reproduction in dementia illnesses is a result of its retention as a form of implicit memory.

How personhood as granted through moral identity is transformed in dementia through cognitive decline is one that directly affects the caregiver and relative. If caregivers perceive the individual with dementia as having lost memory, how then does this affect the two actors's interpersonal relationship? Though the agential aspect of morality may often be seen to have been diminished in old age with the loss of physical capabilities and a decline in cognitive abilities, this does not mean that it has entirely vanished as if never present. Caregivers, whether they realize it or not, may provide illumination themselves into the personhood of their care recipient by describing their capacity for moral agency (i.e, capability to perform moral action).

The persistence of social etiquette and its moral implications can be seen in Emma's mother, adding reliability to Kontos' (2010) observations on dementia patients. There was once a time when Emma could not take care of her mother's hygienic needs, and so entrusted the care of hygiene to her brother and her father. However, when it came to check whether her mother's adult diaper had been soiled, her mother had vehemently refused to let her son and husband take care of her. With an expression that betrays mild amusement in recalling the incident, Emma exasperatedly describes the scene to me,

> and so my brother tried to see if my mother actually have pee in her diaper, and so they tried to have her let go of her diaper, and she cling to her diaper for her life! And she was like 'What are you doing?! What are you doing?!' So she still recognizes this like, I will not say shame, but how to say, the female reserving…

> [...] the privacy of ‘Oh, you’re male? You’re not gonna touch me,’ even though this is her own son.

Her mother had retained cultural values of dignity and privacy where it came to protecting the female body. Recognizing the social indecency that comes with the exposure of the naked body to the opposite sex, her mother attempted to preserve her privacy, and thus her moral standing, by defending who was allowed to participate in this form of personal and intimate care. She acted as a moral agent, with the capability to determine social boundaries that were comfortable for her.

What makes this particular incident outstanding in studies of dementia and old age, is the saliency of the performance of moral agency and presentation of moral standing. Higgs and Gilleard (2016) argue that what is central to personhood is moral agency, and that, “In making the distinction between agency and identity on the one hand, and identity and status on the other, we can treat the former as evidence of the emergent and evolving human capability as a moral agent, while confining the expression ‘the moral status of persons’ to that of an inherently contingent cultural and social trope” (24). As such, Higgs and Gilleard (2016) might attribute personhood to Emma’s mother because she is able to display moral agency through her determination to deter her husband and son from engaging in her personal hygiene care.[16] Contrary to most stereotypical representations of those with cognitive impairments and the elderly, Emma’s mother produced a performance of moral identity through the capability to comprehend her husband and son’s behavior as a breach of social etiquette. With this remaining moral agency, those with cognitive decline retain personhood through the keeping of social

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[16] This is similar to Agamben’s (1998) idea that personhood is hinged on life with value.

etiquette or moral value. Though they may not be able to evolve this agency, it is through performed actions, whether verbal or non-verbal, that they can maintain their personhood.

Balancing agency and standing in moral identity in the care of dementia and Alzheimer's disease patients is not easy, especially when attempting to acknowledge personhood in the face of social attitudes that associate these conditions with a death of identity. These notions of agency (or capability) and standing under the term of personhood must be differentiated, lest the caregiver fall into the pitfall of providing personhood-centered care that ignores the dimension of care involved in viewing those with these conditions as objects of moral concern. That is not to say that individuals with these aging related illnesses should be viewed as objects, only that it is important to comprehend their diminished physical and cognitive capacities in providing care for them. Failure to recognize the distinction between capability and standing in care that takes into account personhood "risks placing the burden of responsibility on other persons, other selves, to sustain the personhood of individuals with dementia [...] as well as sustaining due moral concern for them" (Higgs & Gilleard 2016, 25). The aim is to provide care that respects the individuality and agency of the person to retain their morality, though they may have limited functions to do so. The caregiver does not need to take on the task of maintaining their personhood through forced activities to sustain these capabilities.

The care required that establishes both personhood and does not put undue strain on the caregiver may seem nebulous and unfeasible, but Anne's experience as a social worker underscores the possibility of providing exactly such seemingly complex care. Confronting an agitated patient with dementia, Anne adopted an approach that hinged on distraction rather than comforting the patient, or rationalizing the cause of their emotional distress. This allowed her the flexibility to resolve the patient's distress while giving the patient the agency, the choice, to tap into their personal moral identity if desired. Knowing the patient's background, she prompted the individual to respond to her question that often concerned a value that was important to them,

> For example, I know that elder's background, she is religious person, she like hear the church song, she read the bible - then you distract her, 'Oh, we have a little concert, we can sing the song together,' or 'Oh, I don't understand what is the meaning of this sentence from the bible, can you teach me?' Then she will go back into her teacher mode, she will talk to you [...] You will sit there, just make sure that she calm down. After half-hour, she totally forget why she upset…

Utilizing the understanding of a person's moral agency and standing as distinct from one another, Anne's method of resolving emotional distress enables a form of care that neither denies the elder as an object of moral concern, nor places the responsibility of sustaining agency of the elder on the another. By asking a question that touched on a value and belief system that was of great personal significance to the elder, Anne understood the actions that could be taken by the patient in order to express moral identity. The question gives the patient the agency to respond in whichever way they choose, and the distraction that is embedded in the question takes into account their mental wellbeing, implying that they are recognized as an object of moral care.

Though what may be expressed by Anne's patient in this particular instance is that of religiosity, its characteristics are similar to morality in that it can be considered as a similar internalized value within implicit memory. Additionally, religiosity and morality both have the aspects of being able to be agential and to have a stance within its concept. Thus by asking such an open question that serves the dual purpose of aiding emotional wellbeing and recognizing the potential for moral and religious agency, Anne sees her patients as individuals but understands the status of the diminished cognitive abilities by refusing to rationalize their actions.

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Facing the individual with memory loss due to dementia or Alzheimer's disease calls into question how memory fits into self-concept, as well as what other attributes construct the person, a factor which may prompt the other to reevaluate what they know about that individual with cognitive decline. As the patient with these conditions forgets their relationships with friends and family, it transforms relationships with that individual from one of reciprocity to one-sidedness, pressuring the friend or relative to be the single handed maintainer of that relationship. The label of disease that follows these conditions then leads to a sense of ontological insecurity, where a distinction between a whole and fractured self divides the cognitively healthy from the cognitively abnormal (e.g., one without memory loss vs. one with). The notion of a whole self, must be separated from the one with the fractured self to avoid the threat of contamination from the contagion of dementia in old age. However, the entirety of selfhood does not lie in memory, and these other aspects of self outside of memory tend to be overlooked. Selfhood that is embodied can be found through body language, inflections of tone, and people's taste sensorium, where behaviors unique to that individual are often performed or are on display. Additionally, notions of personhood that rely on leading life with moral value and purpose are not necessarily decomposed in these illnesses of aging. An implicit remembrance (e.g., knowing, rather than recalling) of social etiquette or spirituality may remain, and as such, moral agency, or the capability to act with moral intention, can still be seen in those with dementia or Alzheimer's. These formations of self and personhood redefine the individual beyond being the sum of memories, and this might serve to combat representations of dementia and Alzheimer's as a death of the soul. Even so, it is undeniable that amnesia shifts the meaning of relationships to the individual with these illnesses, as it changes the social and temporal perspectives of one’s own memories as related to that person.

Chapter 3: Associations of Temporality, Memory, and Sociality

There is a paucity of research on how one's relationship with time is affected by conditions of Alzheimer's disease or dementia. What psychological studies have been conducted tend to focus on time estimation, whereas the anthropological work is scarce enough that there are only a handful of authors writing on the subject with no clear trend of interpretation. Conceptions of time can be inconsistent across people and cultures, and the role that agency, illness, and memory play in shifting perceptions and experiences of time are unclear. It should be noted that this chapter relies on caregiver accounts of time as observed in those with a dementia condition, and as such the descriptions given are retrospective, and twice removed from first-hand experiences of time in dementia patients. This chapter seeks to not only add the literature on temporality in Alzheimer's disease and dementia, but it also is intended to contextualize and demonstrate how new temporal dimensions can arise, and how this affects caregiver relationships.

Illness and Linear Memory as Standardized Time

Temporality might be broadly interpreted as the condition of having a relationship with time, a state that can be in movement or static. For example, among the Illongots in the Philippines, time keeping is not a matter of disciplined routine (or the keeping of schedule), but is more similar to a series of disconnected events dictated by the rhythms of socializing (Rosaldo 1989). Moroccan Islamic law is less about the movement of events in simultaneity, but rather about an encapsulation of affiliations that can exist at any given moment (Rosen 1989). That is, rather than conceptualizing time as a sequence of events and their consequences, time is more about a set of relationships that can exist within any moment. On the other hand, conceptions of time in North American contexts tend to be linear, following the chronological sequence of past, present and future. Though taken as a given today, this ‘Western’ linear conception of time only dates back to the Age of Enlightenment (Anderson 2006). Benedict Anderson (2006) suggests that prior to this period, it was thought among the predominantly Christian states that they were ‘near the end of time,’ in that the Second Coming of Jesus could occur at any moment. With events in the Bible interpreted as something that ‘was and shall be,’[17] time was similar to what could be called an instantaneous present, where events were not situated along a chronological continuum but rather happened simultaneously. It was not until the appearance of the novel and newspaper that time as simultaneous conformity, or as Anderson (2006) puts it, ‘homogenous, empty time’ began to form in Western consciousness (this transformation of time being a key factor that was essential for his argument for the formation of nationalism). He argues that without this change in the conception of time, the imagined community of nation-states today could not be possible because the movement of time in the novel was transformed from a beginning to end (from point A to point B) and newspapers marked events that were of note for a particular day across the world, standardizing the passage of time chronologically (specifically calendrically). Since these print creations, time has been linear, and it is the normalized relationship that Westerners (e.g., North Americans) have with time flow.

Illnesses, especially those that are life threatening and/or are conditions of aging, result in a compression of time, where mortality becomes more salient in the scale of a linear lifetime. Terminal stages of illnesses, as well as the severity of symptoms can impact the felt imminence

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[17] With God acting as omnitemporal and therefore having decreed events beyond the earthly time constraint.

of death. The realization that an individual’s physical health is deteriorating has the potential to lead to a restructuring of the day-to-day, where each hour lived becomes another moment survived. Whereas individuals without such ailments are free to think prospectively as far ahead as they like, be that a day or year, persons with life threatening conditions must think in terms of how to deal with imminent death (Kleinman 2020), diminishing the relevance of planning beyond the scope of the time of the predicted death period. With dementia conditions, where there is no pharmaceutical or behavioral cure, and medication can only be used to slow its progression, the time that is interpreted to be remaining for the older adult takes on an urgent quality. As Anne stressed earlier (in Chapter 1), getting early diagnosis in dementia was important so that the diagnosed could get their finances, housing, treatment, and care in order before they became incapable of making these informed decisions. The linear time of agency has become an irreversible absence of life in its approach to death (Greenhouse 1996), and the life threatened by illness in linear time grows imminently closer to its demise in these conditions. As such, time to live without severe onset or until death becomes urgent in its imminent absence. Where the diagnosed older adult’s lifespan may once have been seen as living for another ten years, their lifespan now becomes compressed into the next few months or years as they are seen as closer to death, both socially and physically.

Even as time is now often interpreted as linear, personal individual experiences of time that defy its strict linearity and moderation between past, present, and future can be found within older adults and those with cognitive decline. Older adults have a tendency to incorporate more past personal anecdotes in conversation than those in young or middle-age, and as such, move more fluidly between past and present (Degnen 2005), disrupting the normalized concentration of people's consciousness within the present. The abnormality of this increased movement between these two spheres of chronology (that is, past and present) then creates a temporal category of older adults that is compared and judged against that of younger and middle-aged adults, as the older adult disrupts the flow of normal, socially sanctioned conversation with seemingly irrelevant past anecdotes (Degnen 2005). This distinction is only exacerbated by older adults with the addition of aging related cognitive illness. Psychological studies of time perception, cognitive abilities, and emotional distress in people with Alzheimer's disease and other dementias may compare their results to that of their caregivers, the latter's perception being utilized as a baseline for their care recipients to be measured against (e.g., Maki et al.'s [2012] study). Other studies may compare patients with dementia to age-matched controls, a move which resists the privileging of the middle-aged time concept and adds greater validity to the experiment. Outside of the laboratory, individuals may still describe linear time as the standard and compare those with different time notions to it. This was true of my interlocutors, who used socially shared standards of time to depict the individual with dementia's relationship with time.

In order to describe the dementia person's perceived relationship with time, it requires the one doing the describing to draw upon their memory, a memory that is often valenced within a linear context. They draw on past recollections of that individual, and must compare it to socially ordained explanations of temporality in order to make that individual's experience legible to others outside of that experience. In illustrating their respective grandmothers' perception of time, Karl pulled from concepts of linear time, while Jacob discussed the idea of a "normal consciousness," a state which he described as including the ability to connect ideas of past, present and future. This capacity to make judgements on their grandmothers' statuses and connection to time in itself must involve temporal ordering, a faculty which is intimately tied to memory processing as it includes the placing of events within a linear order, from past to present. Although they may both come from different cultural backgrounds,[18] they are connected by notions of linear time. This could be due to the proliferation of the keeping of a global time, where each country adheres to the Gregorian calendar and marks the passage of time through this chronological system, ensuring that nations are connected through this record keeping. With memory, and to a certain extent consciousness (as mentioned by Jacob), as constructed with linear properties, other concepts and perspectives are affected by this attribute.

This use of temporal ordering is not limited to describing another person's time relationship, and is also used in each interviewee's description of the person with dementia's state of self prior to and after the onset of the illness. The retrospective recall of memories gives specific events importance, or consequence (Orona 2002), so as to become events or things that made the individual with dementia themselves (see Chapter 2 for participant's examples of selfhood manifested in individuals with Alzheimer's or dementia). When I asked my participants whether they noticed any changes or constants in the individual with a dementia condition before and after the onset of the illness, this required them to look back upon their memories to assess whether there were any differences in that person's behavior. Even without prompting, when I asked about what Karl's grandmother was like (she had passed away at the time of the interview), he responded by matter-of-factly asking me whether I wanted to know what she was like before or after. Thus, it might be posited that the subsequent mismatch of events after onset that do not line up with previous memories of the individual's behavior then become signifiers of

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[18] Karl being from China, and Jacob having a Lithuanian heritage culture.

a loss of self. It is only by reference to these past memories that the new ones created come to hold this quality of identity erosion.

Memories, as well as their temporal sequence, are then an interactive practice (Liebing 2006), as it requires both the recall from the carrier of the memory, and the influence of the changing component (e.g., a person) of that specific memory. Changes in the individual with dementia's behavior become more pronounced with reference to previous memories, because it requires updating the specific concept of that person. As these new memories are more often retrieved, they become more easily remembered, whereas competing similar information (e.g., other memories indicative of the other person's self) becomes more difficult to recall in a phenomenon called retrieval-induced forgetting (Abel & Bauml 2015). Linear time may not feature as prominently within those with Alzheimer's or dementia as they experience amnesia or become incapable to form new memories, but the question remains of how their perception of temporality might differ from standardized time.

Memory and Cognitive Behavioral Expressions of Time

Memory is intimately involved with time perception, and many psychological studies will look at the two together in order to assess temporal experiences. The concepts of recency, frequency, order of events, and duration of events all require some form of memory in order to comprehend (Block & Gruber 2014). For instance, in estimating how much time has elapsed between a past event and present, memory is required in order to make an estimate of distance (Grondin 2010). Even prospective estimations or planning requires a mental record, as the ability to form associations between present and potential events is key to predicting duration or executing a future event (Grondin 2010). While there are also phenomenological theories (e.g., chronesthesia, the awareness of subjective time) and sensory modalities (e.g., time to collision, the study of mechanisms involved in judging when an object will arrive at a given point) involved in the perception of time (Grondin 2010), most literature relating to cognitive impairment and aging in time perception involve examining memory rather than these other perspectives. In particular, time perception studies on Alzheimer's disease focus on impaired declarative memory as an explanation for differences observed.

There are relatively few studies on time perception in individuals with Alzheimer's disease or dementia, but what is clear is that memory does affect ability to track the flow of time, and for those with cognitive impairment in which declarative memory is affected, this can have many implications. Once the older adult with Alzheimer's disease and/or dementia begins to display the inability to create new memories or begins to exhibit amnesia, their ability for mental time travel may be impaired (El Haj et al. 2013). This cognitive skill of mental time travel involves the ability to mentally project oneself backward in time/memory. In a study by El Haj et al. (2013) on retrospective and prospective time estimation in those with Alzheimer's disease compared to cognitively healthy old and young adults, they found that there was a trend (the results were not statistically significant) for Alzheimer's patients to give shorter time estimations than the age-matched and younger adults, suggesting that time was perceived to pass by quickly. Prospective time estimation was positively correlated with mental time travel, and retrospective time estimation was even more highly positively correlated with mental time travel. Though retrospective time judgements were underestimated across all groups, the outcome of their study still suggests that cognitive disorders might affect time perception and mental time travel as the

Alzheimer’s patients had given shorter estimations on the whole, implying perturbation in time perception.

Another piece of research on time perception using event date estimation (e.g., judging approximately when a past event occurred) also found evidence that those with Alzheimer’s disease perceived time differently. Using concepts of backward and forward telescoping, the former being misattributing events to earlier dates and the latter being misattributing events to later dates, El Haj and colleagues (2017) compared age-matched older adults and Alzheimer’s patients estimation of dates for remote events. They found a statistically significant difference for remote event estimation by the Alzheimer’s patients, where they exhibited greater forward telescoping than backward telescoping and accurately attributing the correct date. There was also a significant difference between the older adult control group and Alzheimer’s group, where older adults more frequently provided the correct event date than those with Alzheimer’s for remote events. These results might suggest that those with Alzheimer’s disease might indeed experience time to flow by more quickly as previously proposed by El Haj et al. (2013), in that past events appear more recent to them.

These findings were also in accordance with observations made by Anne, Karl, and Emma, where they reported that those they knew with a dementia condition seemed to spend more time thinking about their personal histories. The suggestion that time was perceived to pass quickly (El Haj et al. 2013) is reflected in Emma’s statement on her mother’s relationship to the present. She noted that when her mother was not recalling her memories that she seemed to live in the present, but a present that did not extend past a state of instantaneity: “So sometimes she will say when she sees me in my jacket, ‘Oh, where do you want to go?’ And that’s it. [...] But she will not say ‘Tomorrow you’re going to go here or there.’ That’s already long gone.” Her mother demonstrated having the notion of the next few moments, but in the absence of mentioning a temporal order, such as a specific chronological time or date, she did not appear to think forward ahead of what sensory contextual clues she was presented with at that moment (seeing Emma in her jacket informed her that her daughter was likely to go out). The continuity of an imminent future that occurs as one moves forward in the present did not appear within her mother’s display of planning because she did not think beyond the visual cues she had been given. Being unable to think ahead into the future suggests that time passes by quickly in that there can be no slow passage of linear time without comprehending that there will be another hour, day, week, etc. to pass by.

Anne’s and Emma’s remarks about their relatives with dementia were particularly consistent with the findings that remote events appeared to be closer to the present through forward telescoping (El Haj et al. 2017). Understanding the comfort her mother found in telling stories about her personal life, Emma prompted her mother to engage with her past. Though Emma has heard her mother’s childhood stories “a gazillion times,” her tone is amused and fond, even if she is exasperated by the repetition of hearing these narratives. Anne also encouraged her clients’ to tell her stories about her past (e.g., asking them to talk to her about their experiences in the second World War), although like Emma, she had heard them many times. Underlying both Anne’s and Emma’s observations is that the individuals with dementia did not appear to remember having shared these past personal narratives with them before. Though the persons with dementia conditions did not remember recent events, they were able to recall events that took place much earlier in their life, such as their childhood, or in World War II. The ease of remembering these distant events could be interpreted as having an associative link with greater forward telescoping, as the remoteness of the events appeared to be more within her recall reach than more recent events.

Consistent with the theory that older adults interject conversations with greater past personal anecdotes as a soothing framework and therefore moved more fluidly through past and present (Degnen 2005), Anne observed something similar with her clients. By prompting them to tell them to tell her about their experiences, she felt that they were able to go back to the moment that they most enjoyed. Notably, she did not say that they fully interjected themselves into their pasts as if it were the present, but rather framed it in terms that suggested they relived that event again where they were aware that there was a boundary between these two temporal states. Active intentional recall of the event is required in order to experience those soothing moments. Her clients were aware that they were in the process of remembering, and these forms of temporal navigation are fully grounded in linearity because of the purposeful separation of past, present, and future.

New Temporal Realities

Taking a step back from memory, what does it mean to simply have a relationship with time, such that time can be theorized as an expression of agency? Greenhouse (1996) posits that concepts of time articulate people's understanding of agency through providing a place to describe what makes things happen and what makes these events relevant to social experiences. Though agency may also be a social concept like time, it allows people to comprehend a situation's relevance to oneself. Greenhouse then argues that social time, a pluralistic time that encompasses social experiences, is not defined as a culmination of individual acts, but rather involves cultural meanings of agency made relevant by social crises. Within this project, the social crises made relevant here is that of Alzheimer's disease and dementia. Social time in this project might then involve expressions of agency performed by individuals with these conditions and how their conditions affect their relationships with those around them. The temporal relationships experienced by individuals with these conditions would then be interpreted as a new form of social time that is marked by their condition.

In a grounded theory study conducted in a Japanese nursing home by Shiromaru-Sugimoto et al. (2018) with eleven patients diagnosed with Alzheimer's disease, the themes (or categories) found by the researchers were a new form of time that depicted a degree of agency. The subjects in their study reported five main themes which were respectively labeled as "live life according to a private clock," "the past comes up," "go back and forth between the past and present," "cannot imagine the future," and "bid farewell to this world as early as tomorrow." These five different categories represented views of time that were influenced by their Alzheimer's condition and were shared among them, though these temporal relationships could not be felt by the researchers themselves. The first category, "live life according to a private clock," represents the living of life according to the specific circumstances and conditions they have been placed in, where they live at their own pace rather than pay attention to those around them. This view enables the patients to comprehend their own mental condition's social relevance to themselves, and thus articulates a concept of agential time consistent with Greenhouse (1996). The fifth category, "bid farewell to this world as early as tomorrow," has a similar effect to that of the first category, but places the Alzheimer's time in conversation with the social time experienced by those without the condition. The acknowledgement of imminent death represents a social crisis for both the individual with illness as well as those around them, and as such involves meanings of agential loss through the loss of life. Shiromaru-Sugimoto et al.'s (2018) work lends greater credence to Greenhouse's (1996) notion of time as agency, and also introduces the possibility of new temporal landscapes.

Within my own research through interviews, the perception of these new temporal landscapes are seen in remarks made by Karl and Emma, but their interpretation of their relative's experience in time in contrast to their own temporal experiences calls attention to certain tropes of aging and agency. A question I ask Karl about recognition elicits a lengthy answer about his grandmother's attempt to marry his mother off to her current husband, at a family dinner. Though his mother and his father had been married for years, his grandmother had been unable to remember her own daughter's own marital status, and her son-in-law (who was present at this particular dinner) had been a stranger to her. Karl further followed up his response by elaborating that his grandmother's response was not necessarily indicative of thinking about the past but that "it's more like living in the past, because you're not consciously trying to remember where you were in your brain, but it's more like you just dial back to that." Throughout this interview, Karl had continually referred to time with a dial metaphor, implying he thought of his grandmother as tapping in and out of a past and present continuum. His time metaphor emphasized differences in holistic time, but the way in which he described his grandmother's state in past or present was similar to Emma's description of her mother living in a state of the present, where she did not think ahead into futurity. This implied that their relative's ability to move fluidly in time, or to engage in mental time travel, had been involuntarily revoked.

Unlike the typical conceptions of time as linear such that social events could be placed along a timeline and made relevant to an individual's experience, those with dementia illnesses were not seen to have this capability. Combined, their depictions of their relative's temporal relationship was one that fit common conceptions of old people's out-of-sync state of time.

Particularly, Karl and Emma's comments fit Degnen's (2005) observation from her fieldwork where she argued that "older people are perceived as if they are locked either into the past or into a motionless present. [...] [T]o be categorized as 'old' is also, broadly speaking, taken to mean a stepping out of the flow of time, and in particular, to have one's back to the future and to be preoccupied instead with the past" (59-60). Karl's observations swing back to Degnen's (2005) point of the perception of the old as locked into the past, whereas Emma's note bore greater similarity to the idea of the motionless present. Both of them displayed aging tropes in their illustrations of their relative's time, but it should be noted that neither meant their remarks to be malicious stereotypes of the old. Their choice of words were more representative of how aging illnesses affected time perception in diminishing a person's cognitive abilities connected to memory and lucidity. Even if the tropes of a repeating past or stagnant present are embedded within the states of Alzheimer's and dementia, it does not necessarily mean that they have stepped out of the flow of time, only that they no longer function within linear time.

This use of language that invokes a disconnection from linear time may call into question what it means to be in a state of time that is neither entirely separate nor fully distinct as its own entity. As observed by Karl and Emma, those with Alzheimer's disease or dementia did not appear to experience time with the same rigid, forward-moving, linear concept conceived of in North America, but rather in spaces of time that oscillated between past and present linearity.

The time experienced by those with dementia conditions is something that is perceptible by those without these illnesses, yet at the time, it cannot be fully comprehended or seen by those without dementia, as they inhabit a linear time. To borrow from De la Cadena's (2010) framework on the Indigenous Andean and non-indigenous Peruvian perception of mountains, where she used the phrase 'more than one, but less than two,' to describe the mountain's state as both an earth-being with agency, and an object of nature, time can be seen through a similar view. In this instance, there is no singular temporal reality in the sense that there are two states of time, that of the individual with dementia and the individual without, but there are also less than two planes of time in that the individuals both still share a relationship with this temporality. The two time realities overlap, share a hybrid space-time, and remain distinct.

This space of overlapping but distinct time between caregivers and dementia temporality is exemplified by Jacob's experience with his grandmother. Over our conversation on Zoom, his sentiments expressed at first what seemed to be congruent with Degnen's (2005) observation of stereotypes of old people's time, but his words also subtly underlined a connection to a flowing time, rather than a stagnant experience of time:

> I think we spend a lot of time in normal consciousness, like, looking ahead or thinking back? You know, and connecting the present with what might happen in the future and what happened in the past? [...] whatever is happening in the moment is like, connected to that context? It did- it didn't feel like that existed for her, like there wasn't a sense of what might happen tomorrow or what might happen in an hour, or what had happened just a few minutes ago. [...] She's outside of- *outside of how we experience time*, I guess. But probably… [audio static] *continuous present*, there is no future, there is no past. There's just experiencing what she's experiencing at that *moment in time*. (Italics mine.)

Jacob felt that his grandmother was outside of how we (cognitively healthy) people experienced time, and the inclusion of the particle we to designate time implies that his grandmother is not disconnected from time, but cut off from our version of time. The trope of motionless present in older adults (Degnen 2005) is also not fully expressed here, as Jacob designates his grandmother's present as continuous, implying an uninterrupted function of movement. The effect of these specific vocabulary choices in describing his grandmother's temporal experience makes her temporal relationship in conjunction with his frames time as 'more than one, but less than two' (de la Cadena 2010). His statement acknowledges that her time is different than his, but that she still has a connection to time. That he is able to witness her time through his own implies that there are occasions when her time overlaps with his such that it is observable as a distinct existence.

The experiences of Jacob and his grandmother, as well as Karl and Emma, could be described not only as an overlapping but distinct time, but also as indicative of tempos of social being. These tempos of social being can be described as the rhythm of the tugs and pulls of social life, where social factors introduce variability and indeterminacy into the timing of social events (Rosaldo 1989). Similar to the theme of "live life according to a private clock" (Shiromaru-Sugimoto et al. 2018), where life was reordered to fit the Alzheimer's individual needs through their life pacing, these tempos of social being can relativize experiences of time in such a way that avoids placing individuals without linear time as outside the flow of time entirely. Jacob's experience with his grandmother places her in a different temporal landscape that is still observable to him, and this recognition allows room for the social factors that introduce indeterminacy (such as dementia) to be introduced into his own linear time, accommodating both of their perspectives. Karl's grandmother as living in the past, and Emma's mother as in the present, also display tempos of social being. Although their relative's perception of time might not be construed by them as an abnormal expression of temporality, the social interactions they engage in with their relatives is a participation in a rhythm of time that is influenced by dementia and other social factors. Tempos of social being can thus encompass different planes of time, adding new temporal experiences such as those displayed in Alzheimer's and dementia into social time.

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This chapter has sought to expose assumptions and illuminate perceptions of time among caregivers and those with dementia-related illnesses, and how this affects the social interactions that take place between them. Linear time, though often taken for granted in North American spaces, is often contested once Alzhimer's disease and dementia is manifested. The ubiquity of this linear time is seen in that responses from participants that did not rely on linear notions of time, the involvement of concepts of past, present, or future to describe time in the individual with Alzheimer's or dementia could not be elicited. The answers did consistently report a difference of time perception, possibly suggesting that dementia conditions do have an affect on time perception in the patient. The detriment these illnesses have on memory and other cognitive abilities affects time perception by diminishing mental time travel capabilities, and it has been proposed that time is perceived to pass by quickly in people with these conditions. This difference in time perception does not only have an effect on the individuals with dementia, but also can affect the people they come into contact with through shifts in their presentation today in comparison to retrospective comparisons made by others. New temporalities emerge through their experience of time, and change the social tempo of their life alongside their caregiver.

Conclusion

Throughout this project, I have argued how the relationships of caregivers and those with dementia that they care for are changed upon retrospective memory recall when incongruencies with the dementia person's past and present selves appear. In examining the three themes of caregiving, selfhood and personhood, and temporality, I have synthesized theories to show how conditions of dementia affect the ontology of these concepts, as well as their subsequent effects on people's relationships. The experiences of my six interlocutors embedded in this work form the basis of this project, and it is their perspectives that I drew upon in order to show the reader the many ways in which dementia affects relationships, concepts of self and person, and time.

In the first chapter, I began by discussing the way in which caregivers' relationships with those with dementia conditions are intimately influenced by dementia in order to address the aspect of interpersonal connections (i.e., relationships) in my argument. Thought of as illnesses of aging, Alzheimer's and dementia did not appear to have a sudden onset in the individuals afflicted, and each interlocutor expressed the idea that at first, these conditions had appeared to be normal aging to them. As cognitive decline continued to progress, the relatives and/or caregivers noticed inconsistencies in the care recipient's behavior that then informed them of the degree and type of care these persons needed. The onset of cognitive impairment and behavioral changes altered their relationships, and the caregivers found shifted meanings and emotions in their relationships that they attributed to be a result of the dementia conditions in the individual with the dementia condition. These illnesses of cognitive decline may first and foremost impact the individual diagnosed with these conditions, but the ramifications reach into their social connections to others.

The second chapter turned to address dementia's effect on the concepts of selfhood and personhood present in this project's argument. As each person came into their caregiving role, and they spent more time observing the individual after their diagnosis of dementia, they each compared the individual from prior and post their onset, indicating that the idea of a changed self was a salient theme within their conception of that person. Accompanying these newly questioned selfhoods of those with Alzheimer's or dementia, are the categorization of these people as ill, leading to ontological insecurity about these persons' ability to display full personhood due to their fractured wellbeing. Despite these conceptions, my interlocutors' descriptions of their relatives with dementia conditions did not embed deteriorations of self or personhood. Though they may have thought of these afflictions of cognitive decline as a loss of autonomy or soul, the moments they recollected of each person with dementia were vivid in demonstrations of embodied selfhood and moral agency. This indicates that although dementia conditions had an impact on the conceptualization of selfhood and personhood, these illnesses of cognitive decline did not have an impact on their ability to hold self and personhood.

Lastly, having established how dementia has an impact on relationships, and concepts of self and personhood, I used Chapter 3 to show how the aspect of temporality is essential to the caregiver and dementia person's present relationship as it relates to their relationship from prior to the illness's onset. The manner in which the caregivers had to compare the individual with dementia before and after the signs of illness speaks to retrospective mental time travel, and combined with their observations of their relatives with Alzheimer's or dementia, this indicates the centrality of time in constructing the person with cognitive decline from a secondary point of view. The individuals with dementia conditions were thought to reside outside of standard linear time, but this conclusion was only possible through the comparison of their current temporal relationship to their previous relationship. The existence of these individuals that was outside of normal (that is, the caregiver's relationship with time/temporal reality), might be interpreted as a new temporal plane that is influenced by the changing of their social rhythm. By no longer adhering to chronological time, and instead being greatly influenced by the attributes of their dementia condition, the tempo of everyday life is changed to match their own needs, therefore also changing the way in which their caregivers interact with them. Thus, this changing of the tempo of life prompts the caregiver to reevaluate their relationship to the individual with dementia by looking back upon their past memories and comparing that person's present and past self, thereby changing their relationship.

This work adds to the body of literature that addresses the experiences of dementia from caregiver perspectives, and in particular, expands the social science's discussion of temporality within this particular framework of cognitive impairment. The three chapters in this project have not only provided evidence for changed meanings in relationships upon retrospection, but also have shown the various ways in which dementia can change a person's concept of what it means to have a self, to be human, and to live with time. As I have noted, new expressions of personality and behavior became salient, broadening each interlocutor's understanding of their relatives and what that relationship with that relative was to them, in both emotion and memory. The descriptions of embodied selfhood and new social temporal realities demonstrated new ways in which one could live with dementia. The specific inclusion of time in this project has also addressed the role of social convention and memory in shaping conceptions of time. Comprehending these new perspectives of care, selfhood and personhood, and temporality can therefore also undo the stigma attached to conditions of aging while acknowledging the difficulty of undergoing cognitive decline.

The conclusions presented in this work are, of course, open to contestation. One such counterargument includes the possibility that the meanings found in these relationships would have changed regardless of whether the caregiver engaged in retrospection by virtue of the addition of dementia is founded in the assumption that dementia is obvious as an illness. Yet, these interlocutors often did not show a change in conception of the individual until their diagnosis. It was only when symptoms of cognitive decline were undeniable and could be labeled that each interviewee then thought of illnesses of aging and changed their conception of the individual by being able to look back upon their past behavior. The argument of this project is only one interpretation of the ways in which conditions of dementia connotated with aging can affect the afflicted person and their caregiver, and other inferences taken from the same interviews are wholly possible.

Each participant brought perspectives that were unique to their experiences, but viewed together they began to show a pattern of similarities, as presented in this project. They may each have had their differences and vastly different cultural backgrounds, and so may not resemble others' experiences upon first glance, their words congealed into coherent shared themes. The sum of their views may not directly reflect the reader's own, and as such, these perspectives in this work are only meant to provide a window into the manner in which dementia conditions may affect others and the ontology of certain concepts made salient by virtue of its presence. It is the specificity of their experiences that are meant to be seen so that each narrative provided might reflect the variety of ways in which dementia presents itself.

There is still much to be learned from the experiences of those with dementia conditions, and how dementia affects the ontology of different concepts that we often take for granted besides selfhood and time, such as medicinal practice or aging into elderhood. I think back to what my participants have said and I find bits and pieces of thematic information that I have not fully addressed, as they were beyond the purview of my project. Besides the vastly different cultural backgrounds that each interlocutor has come from, there remains Donna's concern for the state of assisted living, Karl's family dynamics and values, Anne's attention to her client's behavioral status, Jacob's observation of his grandmother's visual acuity, Emma's note of her mother's selective memory, and much more that I have not been able to fully address in this project. There is even a sixth interviewee, Nancy, whose insight I was not able to include because our conversation went far beyond the confines of this work, and into an entirely different topic on aging well and elderhood, rather than dementia.

On a final note, I want to call attention to the warmth and tenderness each interlocutor expressed towards their relatives. Though some of the statements made may have expressed frustration in caregiving, or the stigmatizing experience of the social death of their relative, I got the sense that every action they took in the process of being with their relative was made out of compassion. Jacob put it this way: "I don't know that there was motivation beyond just, a kind of basic, you know, someone I love and she's ill, and I don't know, I'm trying to figure out the thing that can make her as comfortable as she could be, it was kind of simple that way." The continued effort they put into maintaining the relationships with their relatives, even if it no longer was what it was before, came down to the fundamental issue of caring because they loved them. Even after taking into account all the implications, results, unraveling of stigmas, and consequent argument of this project, the feature that brought each caregiver together in emotional commonality was the endearment displayed for the person with a dementia condition.

Appendix A: Interlocutors

In order of appearance:

Donna: Caregiver for her mother with Alzheimer's disease who resided in an assisted living facility. She looks to be in her sixties, and carries herself with self-assuredness and confident composure.

Anne: Social worker and caregiver for her mother with dementia at her mother's own home. She is easy to talk to and energetic about her work. She can go on for minutes on end about her job, and she couples her experiences with how she personally felt.

Karl: Chinese College student who spent time staying with his grandmother while she had Alzheimer's disease. He is in his twenties with an incredibly sharp memory and often speaks with many metaphors. Every personal vignette he provides is rich in detail.

Emma: Indonesian-American University music teacher and caregiver for her mother with dementia at home. She is soft spoken and grounded. During our conversation, she uses her body language and facial expressions to emulate her mother.

Jacob: Architect with graying hair who took care of his Lithuanian grandmother with dementia when he was in his late twenties. He speaks at an unhurried pace and contemplates each of my questions carefully before answering.

Nancy: Caregiver for her father with dementia. She is in her eighties and is full of spirit. Our interview is filled with tangential anecdotes and the responses she gives are elaborated upon with a wealth of Southern Chinese family history.

Appendix B: Semi-structured Interview Questions

All interview questions may have elicited follow-up questions for the purposes of elaboration or further interest in topics emphasized by participants.

- Can you introduce yourself for me? Tell me anything you are comfortable with sharing (e.g., occupation, family, education etc.)
- Can you tell me about how you came to know the individual with Alzheimer's disease/dementia?
- In your experience, has ______ (the individual with AD/dementia) changed since they began exhibiting symptoms of ______ (the condition)?
- In what ways was the person familiar or unfamiliar to you?
- What treatments did you introduce to the patient?
- How has _____ (the individual with AD/dementia) responded to their diagnosis? Have they made any adjustments to their everyday life?
- Does your understanding and experience with AD/dementia differ from that of the individual with the diagnosis?
- In what ways do you see the individual with AD/dementia exercising self-agency or self-determination?
- Do you think the individual with AD/dementia is aware of how their condition is affecting them?
- In your experience, are individuals with AD/dementia often aware of when and where they are?
- How do you think they experience time? Has AD/dementia affected how they perceive time?
- How do you think their memories inform their sense of time and self?
- Do you think the individual with AD/dementia has thought of their immediate possible future? How do you think they perceive their future?
- How do you support the individual with AD if they display changes in their sense of self or time?
- Is there anything else I have not covered that you would like to share, or let me know?

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