The Dissertation Committee for Corey James McZeal Certifies that this is the approved version of the following Dissertation:

Caregiving in Central Texas: The Role of Adult Day Centers

Committee:

Jacqueline Angel, Supervisor

Namkee Choi

Sheldon Ekland-Olson

Ladson Hinton

Harel Shapira

Caregiving in Central Texas: The Role of Adult Day Centers

by

Corey James McZeal

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Dedication

For my grandmother, Lillian Helaire, who died in 2013 from complications of dementia.

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The biggest thanks goes to the 19 interview participants who generously allowed me to learn more about their lives and caregiving experiences. I hope this project reflects their experiences in the best way possible.

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Abstract

Caregiving in Central Texas: The Role of Adult Day Centers

Corey James McZeal, PhD
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Supervisor: Jacqueline Angel

During the 20th century, improvements in medical care and quality of life resulted in greatly increased life spans for all groups in the United States and elsewhere. The result has been an increase in the number of years in which one enjoys good health and a high level of functioning. However, aging populations also result in an almost inconceivable increase in the prevalence of those suffering from dementia. As the number of individuals who survive into their eighties and nineties increases, the burden of dementia care increases for families and society. In this dissertation I examine the sources of care of older individuals with dementia, paying particular attention to the role of adult day center (ADC) in relieving the burden of dementia care for families. Previous research shows that in the majority cases of families provide extensive informal care for an individual with dementia, but the demands of this task can cause tremendous strain due to the nature and progression of the disease. Due to an increase in women's labor force participation since the 1960s, the supply of individuals free to provide unpaid care has shrunk, and those who do provide this care have less time to devote to it (Angel and Angel 2018). This may lead to role strain, where conflict arises due to the competing demands of having multiple roles (Goode 1960). Many families in this situation decide to utilize adult day care to help cope with this burden. ADC is particularly appealing since it provides many support services without the steep cost of nursing homes. Through in-depth interviews and field observation, my project investigates the increased prevalence of ADCs and outsourced care for individuals with dementia through three lenses: first, I analyze the micro-level dynamics of these family units and whether ADCs and caregiving literacy specifically help to reduce conflict, strain, and disorganization. Additionally, I examine the pathways into the caregiving career and ADC utilization. Finally, I present the concept of "caregiving literacy," exploring how caregivers further this knowledge, how it influences ADC utilization, and the role that ADCs play in the acquisition of further caregiving literacy.

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Chapter 1: Introduction

KIMBERLY'S STORY

Kimberly's parents have always been independent. After retiring and moving to the Austin area from another state 25 years ago, they split their time between church, visiting their newfound Texan friends, and spending time with their grandkids. Up until about five years ago, they were completely self-sufficient. Then the nature of their conversations began to change.

> They would go to the doctor and I'd ask them what the doctor said, and they would say, 'I don't know, I don't remember.' Or I'd say, 'Did you ask about this?' and they'd say no, that they would've told them if it was important I'm recognizing this combination of things is getting worse and worse. And I'd get phone calls. More and more calls during the day.

Kimberly's parents were slowly declining. Her father wasn't forgetting as much, but his physical health was deteriorating. On the other hand, her mother seemed to be forgetting more each day, but her body was holding up well. Neither of them seemed interested in being as social as they used to be. Eventually Kimberly noticed that her parents were beginning to isolate themselves. No longer were they visiting friends or going to church.

> They stopped attending things that had given them that extra enthusiasm for life. That kept them engaged, that kept them mentally active. We recognized that [health] was playing a big role but it may have been a bigger role than we realized. But it was self-induced. It was that sense of pride too. They didn't want anyone else to see them not at their best.

Her parents were changing a lot, and Kimberly realized that without an intervention their health and quality of life would crater. So she retired early and oversees all phases of their lives. Although her parents still live in their own home, Kimberly is there nearly every day, and she manages their doctor's appointments, medications, social activities, and any other situations that present themselves. She says that she never foresaw taking on this role, but she "kind of fell into it" because her only other sibling lives thousands of miles away.

By taking on this responsibility, many other aspects of Kimberly's life have changed. "It definitely impacts the whole family. You can't travel, you can't go out of town." If she has to leave the city for any reason, she must establish backup plans for any situation that arises; typically her daughter, who lives relatively close by, is "on call" and maintains communication between her grandparents, mother, and aunt the entire time.

> It's a huge burden on my daughter. Huge burden. And we try not to do that very often, but there are times where we have to take a break. Or there are business things for my husband's company that require us to be out of town. Or you're just trying to continue with your life, you know?

However, attempting to continue life as it had been before has proved difficult. As her parents' conditions worsen, Kimberly has had to dedicate more time to caring for them. They have become more difficult to deal with; her father repeatedly refuses to give up his driver's license and her mother is "reverting to things she hadn't done in years that aren't healthy for her." There are local services available to Kimberly's parents, but options are limited for a variety of reasons: her parents refuse to leave their house and insist on living at home, alone, as long as possible, which makes nursing homes or adult day cares a nonfactor. Even if using a nursing home were an option, facilities that can accommodate both of her parents are extremely expensive. In the end, Kimberly has to do almost everything for her parents because they are either physically or cognitively unable to maintain their independence. While this is an enormous responsibility, she feels like it is a necessary step to take for the sake of her parents' livelihoods. As she puts it:

> The overwhelming sense is that if someone was not able to check in on them much more frequently and go to the doctor's appointments with them, do the follow-up, ask the hard questions…it's going to shorten their lives. So I made that decision.

Kimberly's circumstances mirror those of many other individuals and families who care for those no longer capable of caring for themselves. The consequences of taking on such an intense endeavor are far-reaching, as illustrated by the adjustments her family had to make in their day-to-day activities. By analyzing Kimberly's situation and people like her, we can begin to understand how and why these patterns materialize in these particular ways. Although Kimberly was not able to utilize an adult day care to help her manage her parents' situation, it is becoming a more viable option in the contemporary American healthcare climate. Her case is typical; despite an increase in the number of adult day centers in recent years, the majority of individuals with dementia are not enrolled in adult day center services (Park et al. 2015). Through in-depth interviews and field observation, my project investigates the increased prevalence of outsourced care for individuals with dementia, exploring the pathways into these services and whether they assist in easing caregiver burden and knowledge development.

BACKGROUND: FROM A SOCIOLOGY OF THE PATIENT TO A SOCIOLOGY OF THE CAREGIVER

Until the 1980s, caregiving research may have ignored people like Kimberly since her parents still enjoyed a high degree of independence, even though she was providing an immense amount of care for them. Despite receiving significant assistance from their daughter, Kimberly's parents might not have been considered care recipients due to the fact that they still lived on their own and were able to drive. But it was around this time period that research questions regarding caregiving became more nuanced; from that point and into the 1990s the dominant questions in the field began to revolve around all types of elder caregiving (e.g. care recipients who are non-residential, who also attend adult day care centers, etc.) and the ongoing consequences for those providing it (Pearlin et al. 2001). In the last 30 years, an abundance of research has highlighted the help that a caregiver (CG) in the home settings provides. From these works we have broadened our understanding of the stresses of care and how families differ in the ways they handle challenges (Zarit & Reamy 2012).

Early on in family care research, the majority of studies adopted a stress-burden model, focusing "on the needs of the caregiver or person with dementia in relative isolation" (Nolan et al. 1996). However, Keady's (1999) research drew attention to prior relationships in the care of those with cognitive impairments, suggesting that the context of the caregiving experience is significantly influenced and shaped by these relationships. For instance, within the caregiving dyad, the CG and care recipient (CR) may "work" collectively, separately, or apart. A dyad working together may have amicable negotiations, while a one working apart may never consult each other when decisions are made. This working relationship can be strongly dependent on the type of relationship the dyad experienced prior to caregiving needs arising, e.g. a friendlier early-life relationship may produce a more collective caregiving partnership. This progression of research questions was pivotal to furthering our knowledge of caregiving as a whole. Newer studies have been able to present a clearer picture of not only the physical effects of caregiving (Brown et al. 2003; Vitaliano et al. 2003; Knight et al. 2007; Mills et al. 2009), but also relationship strain among caregivers (Loomis & Booth 1995; Zarit et al. 1998; Bookwala 2009).

This evolution of research questions has also moved beyond the standard individual CG-individual CR relationship and into the broader family unit as a whole within which caregiving takes place. Dyadic and triadic models have been used to explore the role of cognitive impairment caregiving on both family and formal paid caregivers supporting the CR (Whitlatch et al. 2006; Quinn et al. 2012). Although this research gives us a clearer idea of the expansive impact of caregiving (e.g. the impact of caregiving on employment, social relationships, and physical and emotional health), much of it focuses on spousal relationships (Hellström et al. 2007) and fails to comprehensively consider other members of the family unit (Keady & Harris 2009).

Burdens Associated with Caregiving

Strides have also been made in recalibrating early themes that permeated early caregiving knowledge. Additional newer research has suggested that contrary to popular sentiment, many caregivers are not overly burdened (Chappell & Carre Dujela 2008); while there is indeed burden associated with caregiving, in many cases it does not progress to the stage of overflow or inflexibility. Furthermore, the body can potentially adapt to continued exposure to the stressors associated with caregiving (Roepke et al. 2011) and the employment status of some CGs may mitigate stress, strain, and burden (Rubin & White-Means 2009). This may be true in the context that many caregivers do not have to engage in drastic measures such as quitting their jobs, ceasing their social lives, or reducing sleep when faced with the prospect of providing care.

However, caregiving is anything but a simple or predictable process. For caregivers whose loved ones are still capable of handling some daily activities themselves, it may seem like quite a static process, but for many others caregiving is more of a “wear-and-tear” process (Bookwala 2009): caregivers can never fully adapt to the conditions of the care recipient because the circumstances do not remain stagnant for a significant period of time. Indeed, scholarly research has difficulty creating a standard picture of the caregiving experience because it can differ so drastically based on the circumstances, and these conditions can change in the blink of an eye. No matter how capable a sick person is, the caregiving process is always dynamic, and relationships between the caregiver, the care recipient, health care professionals, and other family members constantly transform. And for caregivers, even when they are not actively providing care, their minds are never idle. There is a constant exercise of envisioning the gamut of possibilities that the next day will bring. Will tomorrow be a bad day for them? Will it be the day I have to rush them to the hospital? Will they even remember who I am in the morning?

Due to the great deal of uncertainty and adjustment frequently accompanying caregiving, coupled with its often time-intensive nature, the caregiver's other roles can be severely disrupted. For instance, Pearlin (1999) argued that occupying too many roles relative to resources could generate stress and ultimately role strain, which is negatively associated with overall health. Carr & Umberson (2013) outlined the context of stress and its potential consequences. A stressor is "any environmental, social, biological, or psychological demand that requires a person to adjust his or her usual patterns of behavior." The impact of stressors on health and wellbeing is not universal, but can vary based on other factors and the CG's access to resources. Likewise, exposure to stressors is not randomly distributed in the population, but is structured and represents patterns of inequality and social roles. There are three major categories of stressors: life events, chronic strains, and daily hassles.

A life event is an "acute change that requires adjustments within a relatively short period." The impact of a stressful life event depends on four factors: magnitude, desirability, expectedness, and timing. In the context of caregiving, a high *magnitude* life event would be one in which the caregiving need is tremendous. For instance, CRs who cannot bathe, eat, or use the bathroom on their own place tremendous responsibility on their CGs. The CR may have to learn new skills, rearrange their preexisting routines, and/or completely abandon current responsibilities to provide such extensive care. Daily activities involve carrying out social roles, and each of these is accompanied by a set of norms and expectations to guide our performance (Biddle 1979). The expectations associated with a high magnitude life event are likely to require the greatest degree of role adjustment since it involves the most effort to fulfill the new role. Additionally, the norms of care in a high magnitude case may vary wildly from usual. For example, CRs who are extremely physically limited may require assistance bathing. This can upend existing rules for behavior, as the CG must see the CR nude, bathe their entire naked body, and dress them again. Prior to the high magnitude life event, bathing may have been a private event that the CR had handled independently for their entire lives. The adjustment to this new responsibility may be stressful for both people involved, especially if there are multiple high magnitude tasks associated with one individual CR.

Desirability refers to the CG's eagerness or willingness to take on the role of caregiving and the ensuing responsibilities. Some individuals may welcome the idea of becoming caregivers for a variety of reasons. Perhaps this person has been a caregiver before, they enjoy the task of providing care, or they welcome the opportunity to help someone they love or care about. In these instances, the event of becoming a caregiver may not bring about as much stress as it would if they had no desire to become a caregiver or were pessimistic about the proposition of providing care to someone.

Included in the measurement of desirability is *salience*, which is "the importance of the role to the individual (Carr & Umberson 2013). While the number of roles held is still a tremendously important variable, recent research has begun to emphasize salience over the number of roles held. Any type of strain is particularly harmful when it is the product of a highly salient role; if the role is undesirable the effects are exacerbated.

Expectedness refers to how much the CG anticipated the upcoming caregiving role. If providing care to a sick family member, caregiving may be more expected if the CR has suffered from a condition that has slowly worsened over time. In that situation, the CG may have more time to prepare for the upcoming responsibilities and adjust to the changes that the CR is experiencing. Conversely, if the CR has a sudden health crisis, such as a stroke, that leaves them abruptly debilitated, the caregiving unit may be forced to hastily create a network of care or rearrange their current obligations to accommodate the situation.

Timing refers to how well the caregiving responsibility integrates with the CG's existing roles. If the need for care provision surfaces while the CG is managing other obligations that require attention and devotion, they may not have ample time to allot for providing care. Furthermore, someone who already possesses many roles may become overwhelmed with the addition of the caregiving role. Some obligations associated with caregiving may be at odds with existing roles (Stephens et al. 2001); the caregiver may not have the time, money, or experience to adequately juggle these roles simultaneously. CGs may even be caregivers on multiple levels (DePasquale et al. 2017): some who are long-term care employees may combine their occupations with unpaid informal care of their children (double-duty child CGs), older adults (double-duty elder CGs), or both children and older adults (triple-duty CGs). Moreover, some CGs provide care for both their children and their parents (sandwiched caregivers). In order to provide sufficient care, one might have to cut back on paid employment hours, reduce their number of community and social activities, or spend less time with other members of their family. Reducing or abandoning a role that the caregiver attaches great meaning to in order to provide care can potentially cause great distress.

However, in some instances the CG may experience role enhancement, which is when "persons who hold multiple roles may find that difficult stressors in one role are counterbalanced – rather than amplified – by successful experience in another role" (Carr & Umberson 2013). In this case, a double-duty child CG may feel more prepared to provide childcare based on the skills they internalize at work. Vice-versa, a double-duty elder CG may feel more prepared than average to become a nurse since they have encountered similar responsibilities while caring for their parent.

Carr & Umberson define *chronic strains* as "persistent and recurring demands that require adaptation over sustained periods." If caregiving requires months or years of efforts from the CG, it may develop into a chronic strain. These strains tend to be powerful predictors of health, and their presence is associated with negative consequences in both mental and physical wellbeing. *Daily hassles*, which are "minor events and occurrences that require adjustment throughout the day," are not as strongly associated with negative health outcomes. They may require a small amount of effort daily or a few times a week, and rarely rank highly in magnitude. In the context of caregiving, a daily hassle may include picking up medicine from a pharmacist, making a phone call on behalf of the CR, or checking their mail. While these tasks may be required of those providing a larger caregiving burden, individually they tend to have minimal impact on the CG's life otherwise.

However, stressors rarely occur in isolation (Carr & Umberson 2013). Primary stressors, which are those that arise from physical demands of providing daily assistance (e.g., helping with toileting, bathing) and emotional demands of accepting and managing cognitive and behavioral symptoms, may be anticipated at the beginning of the caregiving process (Ornstein & Gaugler 2012). But a life event can directly cause new chronic strains, called secondary stressors; vice-versa, the accumulation of chronic strains can lead to a taxing life event. For example, unexpectedly becoming a daily CG for a cancer-stricken parent may prevent them from regularly meeting deadlines at work or being forced to miss out on social activities. On the other hand, the chronic strain of having to accompany the CR to multiple doctor's appointments per week may contribute to the CG missing out on an important promotion or losing their job altogether.

The responsibility of caregiving may not directly lead to other external stressors, but instead contribute to the CG's acquisition of poor health habits. Compared to non-caregivers, CGs have greater odds of overall negative health behaviors, smoking, and regular soda and fast-food consumption (Hoffman et al. 2012). This may be a consequence of convenience, since quick meals may be the handiest option for time-squeezed CGs. There is also evidence that CGs may have poorer self-monitoring (Vitaliano et al. 2017); based on the timing of caregiving, some CGs may become more occupied with sustaining the health of the person they care for than their own. Even those who maintain an aspect of health monitoring in their lives may not be able to be as consistent or thorough in these practices.

The CG's personal resources and individual characteristics also strongly influence the degree to which stressors influence health and wellbeing (Gayman et al. 2017). Such factors may include:

1. Socioeconomic status (SES)
2. Mastery – the sense that one has control over life circumstances and/or outcomes (Pearlin & Schooler 1978), which is associated with fewer depressive symptoms (Turner & Lloyd 1999)
3. Self-esteem – one's own sense of self-worth (Rosenberg 1979); high self-esteem is associated with lower prevalence of depressive symptoms

Those with higher SES may be better suited for outsourcing some of the stressful labor associated with caregiving, reducing their exposure to potentially distressing situations. A CG with high mastery, whether their perceptions are accurate or not, may feel less anxious about their role as a caregiver due to their confidence that they can fulfill their obligations adequately. And the ability to maintain a high degree of self-esteem in the midst of high-magnitude caregiving responsibilities can prevent a caregiver from burning out in their role. Realistically, CGs can be "both burdened and simultaneously experience good or high wellbeing" (Chappel & Carre Dujela 2008). High burden does not necessarily reflect low quality of life, and factors such as mastery and self-esteem contribute to this phenomenon.

Overall, caregiving can be the source of many strains that require adjustments in current roles or acquisition of new roles. In either scenario, frictions may develop from the rearrangement of the CG's obligations for themselves and to others. When these tensions arise, dementia CGs and their families may look to external entities to reduce or eliminate these strains (Zarit et al. 2011).

Demography of Caregivers

Caregiving may feel like an individual burden for a family unit, but in actuality it is a widespread problem with far reaching implications for the society at large. In 2010, older adults 65 and over made up 13% of the U.S. population, and will account for at least 20% by 2030 (Bookman & Kimbrel 2011). Central Texas, which is the field site of my study, mirrors these trends. The area consists of a five-county core-base metropolitan statistical area (U.S. Census 2015). The largest cities in each of these counties are Austin, Bastrop, Lockhart, Round Rock, and San Marcos. Austin saw the largest percentage increase in the population 65 and older, increasing by nearly one-fourth. The city of Round Rock saw its older adult population nearly double since 2000. Even smaller cities, such as Bastrop and San Marcos, have seen significant surges in their 60+ populations (while Lockhart, the smallest of the cities in the area, has seen a miniscule decrease).

City	2000 total population	2010 total population	Percent change	2000 65+ population	2010 65+ population	Percent change
Austin	672,963	790,390	+17.45%	45,257	55,695	+23.06%
Bastrop	5,513	7,218	+30.93%	817	1,102	+34.88%
Lockhart	11,728	12,698	+8.27%	1,578	1,542	-2.28%
Round Rock	61,484	99,887	+62.46%	2,758	5,413	+96.27%
San Marcos	35,597	44,894	+26.12%	2,564	2,993	+16.73%

Table 1: Demographic Change of Older Population in Central Texas: 2000-2010 [Source: U.S. Census (2012)]

Dementia, the main focus of my research project, represents a significant challenge for the 65+ population and all older adults given the nature of the disease and the subsequent consequences for their families. Early-onset (pre-age 65) dementia is especially problematic, as these individuals have a strongly elevated mortality risk when compared to their non-dementia peers (Koedam et al. 2008). Early-onset dementia can also lead to premature job loss and other unforeseen consequences. In 2016, total payments for health care, long-term care and hospice were estimated to be $236 billion for people with Alzheimer's and other dementias, with just under half of the costs borne by Medicare (Alzheimer’s Association 2016).

Although there are various types, the Institute for Dementia Research and Prevention (IDRP) defines dementia as a “decline in cognitive functioning from the previous state.” Alzheimer’s disease, the most common type, accounts for up to 70% of cases. Unlike some other dementias, it can affect multiple aspects of an individual’s cognitive functioning, including memory, language, and personality (Institute for Dementia Research and Prevention 2016).

According to the Alzheimer's Association, 5.4 million Americans were living with the disease in 2016. Without an effective treatment method, there will be a projected 16 million people living in the United States with dementia by 2050. Although it is mostly characterized by declines in cognitive functioning, it has a significant impact on mortality compared to other physical conditions; among Americans 70 and older, those with Alzheimer's are 31% more likely to die before age 80 than those without it. Additionally, among the top 10 causes of death in the United States, Alzheimer's is the only one that cannot be prevented, cured, or slowed (Alzheimer's Association 2016).

Number of Texans with Alzheimer's Disease (2010)	340,000
Number of unpaid caregivers in Texas (2010)	852,820
Hours of unpaid care provided by Texans annually (2010)	971,191,823
Annual cost of care borne by unpaid caregivers in Texans (2010)	$11,168,705,965
Total hospitalization charges in Texas due to Alzheimer's (2009)	$65,000,000
Estimated annual cost to Texas businesses in health care coverage and lost productivity due to Alzheimer's care (2007)	$7,200,000,000

Table 2: Cost of Alzheimer's Disease in Texas [Sources: Texas Alzheimer's Research Consortium (2007); Texas State Plan on Alzheimer's Disease (2010); Lakey (2012)]

Issues Associated with Aging and Dementia

Even in the absence of dementia, the aging process presents many potential challenges for older adults. Various diseases, disorders, and the general nature of aging leave many unable to engage in a healthy level of physical activities. Many older adults are sedentary, indicating that they either do not participate in physical activities or perform physical activities in a seated or reclined position (Tremblay et al. 2010; Owen et al. 2011). Older adults have the highest levels of physical inactivity and are the most sedentary age group in the United States (de Rezende et al. 2014), while nearly 94% are sedentary for more than 8 hours daily (Copeland et al. 2015). This pattern of inactivity is associated with a wide range of negative health outcomes (Owen et al. 2010; Dogra & Stathokostas 2012), although this trend varies by race and ethnicity (Manly and Mayeux 2004).

However, research by McEwan et al. (2017) suggests that despite being aware of the dangers of inactivity, older adults knowingly engage in many sedentary activities and perceive these actions as positive rather than negative. There is a general aversion to the admission of being sedentary, as older adults often associate it with undesirable stereotypes. Thus, older adults look to the bright spots of their situation rather than the reality of their immobility. For instance, they highlight the social or cognitive benefits of their activity level rather than acknowledging the lack of movement that these activities require. Consistent with Social Identity Theory (Haslam et al. 2009), belonging to a group that is perceived as inferior can be threatening to wellbeing and self-image. Indeed, there are benefits to seated activities or those that do not require extensive movement (Phelan et al. 2004; Basak et al. 2008; Nimrod 2010; de Rezende et al. 2014; Bleakley et al. 2015; O'Neil & Dogra 2015) and this alternative is desirable as compared to not engaging in any activities at all.

Maintaining a positive self-image in the context of aging is tremendously important for quality of life. Even those who are experiencing cognitive impairments may be very aware of their conditions. Due to the magnitude of changes that an aging adult may experience, negative correlations (such as depressive symptoms) are common. Older adults with any form of cognitive impairment who are aware of their diagnosis report lower average satisfaction with daily life, basic functioning, and physical wellbeing while experiencing more difficulties in daily life than those who are unaware of their conditions (Stites et al. 2017). Additionally, it is common for those expecting their condition to worsen to report higher stress and lower subjective quality of life compared to others. Dementia risk is also associated with loneliness and having fewer close relationships in late life, so maintaining morale is a high priority in this age group.

Due to mortality, older adults tend to have smaller networks of people their age to socialize with, and those with physical incapacities may not have the means to consistently seek out such interaction. Many CGs cite the moment the CR has to give up their driver's license as a major event in the aging process, one that may represent a loss of freedom or autonomy. Indeed, research suggests that "driving cessation is associated with reduced network of friends, increased depressive symptoms, and decreased out-of-home activities" (Marottoli et al 1997; Marottoli et al. 2000; Mezuk & Rebok 2008).

Dementia can exacerbate the above symptoms while presenting the opportunity for a multitude of additional issues. For individuals with dementia (IWDs), it may be difficult or impossible to maintain social ties or to form new ones due to their condition. Dementia, in conjunction with other disabilities that arise throughout the life course, can put CGs in the difficult position of managing or maintaining nearly every aspect of the CR's life. Table 3 illustrates some of these difficulties.

Emotional	Cognitive	Physical	Social
Feeling moody or withdrawn, especially in socially or mentally challenging situations	Lose awareness of recent experiences as well as of their surroundings	Need round-the-clock assistance with daily activities and personal care	Have increasing difficulty communicating
Confusion about where they are or what day it is	Problems coming up with the right word or name	Trouble controlling bladder and bowels in some individuals	Challenges performing tasks in social or work settings
Personality and behavioral changes (suspiciousness and delusions or compulsive behavior like hand-wringing or tissue shredding)	Being unable to recall their own address or telephone number or the high school or college from which they graduated	Changes in sleep patterns, such as sleeping during the day and becoming restless at night	
	Losing or misplacing a valuable object	Experience changes in physical abilities, including the ability to walk, sit and, eventually, swallow	
	Increasing trouble with planning or organizing	An increased risk of wandering and becoming lost	
	Forgetfulness of events or about one's own personal history	Become vulnerable to infections, especially pneumonia	
	Forgetting material that one has just read		

Table 3: Common Symptoms Specific to Dementia [Source: Alzheimer's Association (2017)]

In the DSM-5, cognitive impairments that do not surpass the threshold of dementia are characterized as minor neurocognitive disorders (Simpson 2014). The criteria for minor neurocognitive disorders includes two factors:

1. "Evidence of modest cognitive decline from a previous level of performance in one or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual motor, or social cognition)"
2. "The cognitive deficits do not interfere with capacity for independence in everyday activities (i.e., complex instrumental activities of daily living such as paying bills or managing medications are preserved, but greater effort, compensatory strategies, or accommodation may be required"

On the other hand, the DSM-5 classifies major neurocognitive disorder as "a condition characterized by a progressive, irreversible decline in mental ability, accompanied by changes in behavior, personality, and in the late stage, motor functions" (Swartout-Corbeil & Davidson 2015). The cognitive losses must be in more than one of the memory, attention, learning, language, perception, or social interaction domains and must be severe enough to impair the individual's ability to function in major ways.

Specific Issues Associated with Dementia Care

Along with the typical issues associated with caregiving responsibilities, those who are caring for those with dementia can face especially difficult circumstances. The disease is often a long-term condition, paving the way for potentially chronic strains for the CG and a greater degree of care difficulty than is common for other types of lingering conditions (Ory et al. 1999). Management of the CR can be frustrating due to the cognitive impairment they are experiencing, compounded by the deteriorating physical condition many individuals with dementia undergo. For instance, 90% of individuals with Lewy Body dementia are unable to perform complex or intellectually demanding activities (Galvin et al. 2010). Compared with non-dementia caregivers, dementia caregivers are more than 40% more likely to experience increased frailty by the time of the CR’s death (Dassel & Carr 2016). Figure 1 illustrates the prevalence of common symptoms exhibited by dementia caregivers.

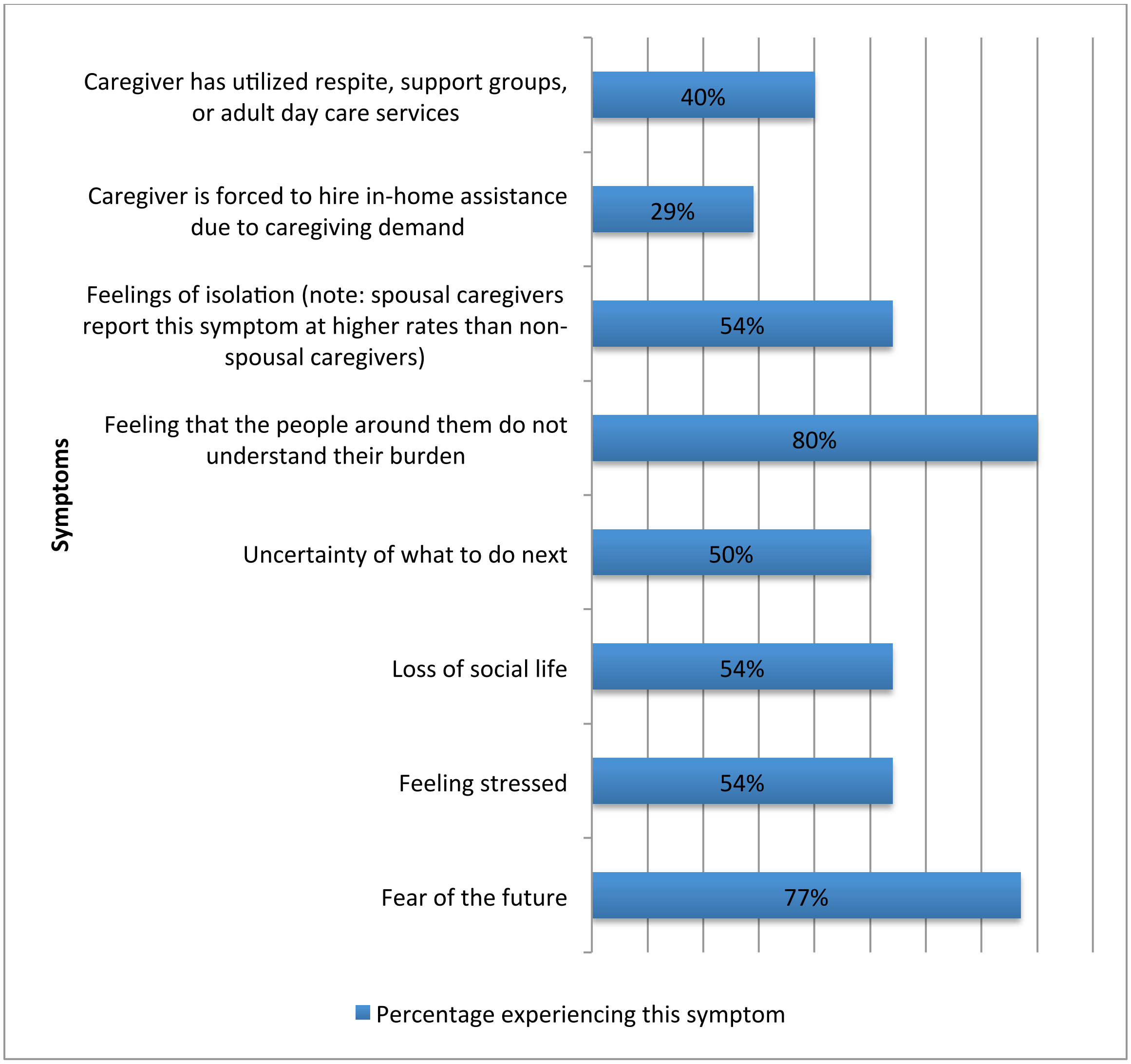

Figure 1: Common Symptoms Experienced by Dementia Caregivers [Source: Zarit (2010)]

It is estimated that the annual cost of informal, unpaid care for IWD ranges from $470 to $522 billion (Chari et al. 2015; Reinhard et al. 2015). These tremendous costs are mostly due to the lost economic production of caregivers who either reduce or eliminate their paid work to serve as caregivers. Additionally, these high costs include the increased medical expenses of CRs incur as a direct result of caregiving and its associated stressors (MetLife 2011).

CHARACTERISTICS OF ADULT DAY CENTER PARTICIPANTS

While there were only about 15 ADCs in the United States in 1975, by 2002 that number surpassed 3,400 (Abramson 2009). They trace their origin to the 1940s when adult day services began in psychiatric hospitals, primarily to assist patients following their release from mental institutions (NADSA 2017). In the 1960s they began to shift from a single psychiatric focus to providing other health services while expanding to more states across the U.S.

Due to their growth and diversification, in 1978 ADC owners and managers "established a national standard criteria in order to allow caregivers the ability to rate and fully understand what adult day centers would provide to their loved ones" (NADSA 2017). The National Adult Day Services Association was formed in 1979, and as of 2014 NADSA has identified 5,685 adult day programs operating in the United States. According to NADSA, over 260,000 participants and family caregivers are serviced annually – an increase of 63% since 2002.

While there can be variation across ADCs, in general they aim to accomplish the same goals. ADCs typically assist families by providing a place for them to bring care recipients during the workday, so individual caregivers can either have a break from their role or engage in paid labor without the worry of leaving their loved ones at home unmonitored (Alzheimer's Association 2017). Nationwide, the average capacity of an ADC is 40 people; the average care recipient-to-staff ratio is 6:1 (NADSA 2017).

The National Health and Aging Trends Study (NHATS) "fosters research to guide efforts to reduce disability, maximize health and independent functioning, and enhance quality of life at older ages" (NHATS 2017). It was designed to follow adults age 65+ and who are enrolled in Medicare. Using this data, we can present a clear representation of the aging process for older adults in the United States, as well as those who care for them. Analysis by Wolff et al. (2017) highlighted the significant aspects of the NHATS as it pertains to caregivers and older adults.

From the data, we observe that the vast majority (93.1%) of the 45.3 million adults age 65+ in the United States live in the community. This may include those who have caregivers, but they are distinguished from those living in nursing facilities (2.5%) and residential care facilities (4.4%). Residential care facilities differ from nursing homes in that they often feature apartment-like spaces for the occupants while still providing a degree of support as needed. Nursing homes tend to be geared toward those who require more direct assistance than those in residential care facilities. Of those living in the community, 11.5% receive assistance from family members or some other unpaid caregiver.

Additionally, Wolff et al. illustrated a demographic snapshot of older adults receiving care, further stratified by the relationship to their primary CG (spouse, child, or other). Data is presented for both the 1999 and 2015 samples. Overall, individuals are receiving care at younger ages, as demonstrated by the 13.4% increase in 65-74 year olds receiving care. Additionally, although the majority of those providing care are women, the share of male CGs increased by 3.1% between 1999 and 2015. In the same time period, fewer whites were providing care, and the share of other racial groups increased by 6.6%. Data was not available on Hispanic origin in 1999, but in 2015 6.5% of all CGs identified as Hispanic. Two of the sharper trends from 1999 to 2015 involved educational and marital status. From the first wave to the second, the number of CRs with 12+ years of education increased by 29.3% and the number of married CRs increased by 12%.

Further analysis illustrated the characteristics of primary family and unpaid caregivers, again for 1999 and 2015. This data reveals that adult children who are CGs are much more likely to be female than spousal caregivers are (71.4% vs. 54.7%). Additionally, the mean age of caregivers for both children and spouses has decreased slightly. Surprisingly, more CGs of parents (25.6%) report that they are in poor health than those who are spousal CGs (21.7%). Table 5 also reveals that the CG's proximity to the CR is a significant factor in caregiving. The significant majority (77.4%) of CGs live with the person they are providing care for, while another 16.1% live within ten miles of them.

The study went on to explore specific caregiving experiences between 1999 and 2015. For both adult child and spousal CGs, the duration of care is increasing. For those caring for parents there has been an 11.6% increase in those providing care for 4+ years, while the number providing care for less than one year has declined by 8.0%. Among spousal CGs, there has been an 18.6% increase in those providing care for 4+ years, while the number caregiving for less than one year has declined by 11.4%. Despite this trend, spousal caregivers spent nearly 17 fewer hours per week providing care in 2015 than in 1999. Both adult child and spousal CGs significantly increased their use of support groups and respite care in the same time period.

To conclude, Wolff et al. detailed the characteristics of CGs stratified by the dementia status of their CR. Roughly ¼ of all family and unpaid CGs provide care for those with dementia. Dementia CGs spend significantly more hours providing care than non-dementia caregivers (47.5 hours vs. 23.5 hours), and 40.4% of dementia CGs spend more than 40 hours per week providing care (as opposed to 19.1% of non-dementia CGs). Dementia caregivers are also more likely to have a co-residing dependent child, more likely to be employed, and utilize support groups and respite care at higher rates.

REDUCING ROLE STRAIN THROUGH SOCIAL SERVICES

Since there is no singular caregiving experience, its influence on wellbeing can vary greatly depending on the context. Overall, CGs are more likely than noncaregivers to experience emotional fatigue, constrained friendship networks, and reduced opportunities for cultural and recreational activities (Gaugler et al. 1999; Cass 2007). Conversely, caregiving is not always a burdensome endeavor; there is evidence that in certain contexts, caring for a loved one can be a moving and enriching experience (Fingerman 2001) and that caring for a spouse at least 14 hours a week is actually associated with decreased mortality (Brown et al. 2009).

Among those who are experiencing burden, such as Kimberly, caregiving appears to be a very individual problem. In many ways CGs treat it as such; a common theme in the conversations I have had with CGs over the past year and a half is that many of them do not often speak about the process to anyone beyond their immediate families. In some cases, even close friends do not know a person has become a caregiver until months after the fact. The caregivers I have encountered often attempt to hold everything together on their own when their loved one is first afflicted. However, at a certain point many realize that they need some sort of intervention to assist them. For a variety of reasons, both caregivers and care recipients are often resistant to full institutionalization in nursing homes. The utilization of adult day cares are often a more viable and appealing option for all involved. Among the community-based long term care options, ADCs may be more favorable alternatives to nursing homes because they allow individuals to stay in the community and provide respite to CGs.

Types of Long-Term Care Available

The individual(s) with dementia (IWD) and their families have a few options when it comes to formal assistance: adult day centers, in-home care, residential care, respite care, and hospice care. While each one can be useful in varying ways, access to these services is not equal. The ability to "age successfully" by making good choices is not universal, but shaped by structural factors (Abramson 2015). People with more resources often age in senior communities with robust social services, while those with fewer resources may only be able to utilize hospice care at the very end of their loved one's life. According to the Alzheimer's Association (2017), the differences in care options are as follows:

Adult day center (ADC) – provides a break to full-time caregivers, giving them time to rest, run errands and finish other tasks. They are especially beneficial to caregivers who work during the day. I will elaborate much more on ADCs in the subsequent chapters.

In-home care – includes a wide range of services provided in the home rather than in a hospital or other care facility. There is great variety in these services; some provide non-medical help while others involve medical care given by licensed health professionals. Medicare may cover certain costs if the IWD meets eligibility criteria. From 2005 to 2015, the number of workers providing in-home personal assistance to the elderly, the chronically ill, and individuals with disabilities nearly doubled to 1.7 million (Hartmann & Hayes).

Residential care – a communal living environment; these facilities provide care and address issues surrounding nutrition, care planning, recreation, and medical matters.

Residential care includes assisted living, where an individual chooses which services they receive from the staff, and nursing homes, where 24-hour care is provided to all residents. Residential care is typically utilized when the IWD has progressed to the point where they can no longer be cared for at home by informal caregivers. The national average cost for basic annual services in an assisted living facility is $41,724; nursing homes average $78,110 per year for a semi-private room and $87,235 for a private room.

Respite care – an umbrella term referring to any service in which the caregiver is provided temporary rest from caregiving while the IWD continues to receive care in a safe environment. This includes some of the services detailed above, such as ADCs and in-home care, but can also include informal breaks provided by volunteers and family members. Due to these dissimilarities, cost varies.

Hospice care – care provided to those who are terminally ill. The primary purpose is to manage pain and other symptoms during the last six months of life where treatment focuses on comfort rather than curing the underlying disease. The majority of hospice care is provided at home or in a nursing facility. Costs are usually covered under Medicare, as well as many Medicaid and private insurance plans.

Other Potential Sources of Support for Family Caregivers

No matter the kind of care and how often an individual is providing care, social support is universally acknowledged as a positive factor in their lives. Social support can come from family, friends, neighbors, co-workers, social clubs and organizations, day care centers, etc. (Strozier 2012). This support can enable more effective coping by giving the CG someone to talk to, reduce responsibility by sharing tasks, or ease mental strain by offering a break from care obligations. Overall, mortality for those with the most social ties is half than that of those with the fewest social ties (Umberson & Montez 2010), illustrating the importance of these entities for overall wellbeing. Various forms of social support may be better sources of relief for varying groups. Churches, long a source of multifaceted support in many communities, are correlated with lower levels of serious psychological distress in African American men, who have a long history of discrimination-related stressors (Nguyen et al. 2018). For double- and triple-duty caregiving women, the role of their husbands as sources of social support is strongly associated with job retention (DePasquale et al. 2017). In the context of CGs providing multiple layers of care, maintaining strong marital relationships to encourage positive marriage-to-work spillover is an effective practice for retaining double-and triple-caregiving employees.

The convoy model of social relations (Antonucci 2001) posits that each individual has a social network, or convoy, that follows them throughout the life course. Whether this convoy consists of structural support, community organizations, friends, etc., having a strong convoy is advantageous. Although individual components of a convoy can come and go, the size and diversity of a convoy can have real effects on health and happiness. Larger, more diverse convoys are beneficial because in a time of need the components of the convoy can be activated for assistance. A small convoy with homogeneous membership cannot provide a wide range of assistance, but a large and diverse convoy can. Furthermore, a positive convoy (one where the components are available and supportive) is more beneficial than a negative convoy (one where the components are absent and unsupportive). A diverse and positive convoy is associated with much better caregiver health, even in contexts where the caregiver is burdened (Sherman et al. 2013). This support can make life easier on the caregiver since such convoys can be activated whenever the need arises. Social support can buffer stressful events by increasing feelings of belonging, elevating self-esteem, providing a heightened sense of security, and increasing the ability to cope (Strozier 2012).

ORGANIZING FRAMEWORKS AND GOALS: UNDERSTANDING THE CAREGIVER CAREER

For many families, ADCs are the most appealing of these options for those with dementia since they provide many social support services without the steep cost of some other types of care. Likewise, as illustrated earlier in the chapter, the utilization of ADCs has increased tremendously in recent years with a 63% increase since 2002. However, not all families turn to ADCs, even when confronted with similar circumstances. Why is this the case? Despite the growing prevalence of ADCs, why are there so many caregivers who are not using them? By analyzing who uses (and does not use) ADCs and how these facilities influence the dynamics of the family unit, we can begin to understand the position they occupy within the large spectrum of care options and why we observe the trends that we do.

In this project, I investigate the increased prevalence of ADCs and outsourced care for individuals with dementia through three lenses: first, I analyze the micro-level dynamics of these family units and whether ADCs and caregiving literacy specifically help to reduce conflict, strain, and disorganization. Additionally, I examine the pathways into the caregiving career and the factors that influence ADC utilization. Finally, I present the concept of "caregiving literacy," exploring how caregivers further this knowledge, how it influences ADC utilization, and the role that ADCs play in the acquisition of further caregiving literacy.

Kimberly's story exemplifies the uncertainty and instability that caregiving can bring upon a family unit; it is not a static or linear process, but one that undergoes a constant, yet uneven, metamorphosis. The above sections exploring the current state of adult day care services illustrate the wide variety of options and experiences family units must navigate when attempting to alleviate stress and strain as a result of caregiving. Through in-depth interviews and field observation, my project investigates the increased prevalence of ADCs and outsourced care for individuals with dementia through three lenses: first, I examine the pathways into the caregiving career and the factors that influence ADC utilization. Additionally, I present the concept of "caregiving literacy," exploring how caregivers further this knowledge, how it influences ADC utilization, and the role that ADCs play in the acquisition of further caregiving literacy. Finally, I analyze the micro-level dynamics of these family units and whether ADCs and caregiving literacy specifically help to reduce conflict, strain, and disorganization.

My analysis of caregivers will employ Becker's concept of careers. Becker's work on medical students (1961) and deviant subcultures (1963) illustrates how acquiring a new identity as a student or deviant is not something that happens in an instant, but is a cluster of separate events; this string of events pushes the individual farther along the path of their career. This approach is useful for framing the caregiving career in the same way: as a dynamic process involving multiple, shifting stages. The career may include a number of transitions, such as the onset of institutionalization, along with the progression and changes in the care provided; based on these factors, there are numerous trajectories that the career can take depending on the context (Gaugler & Teaster 2006).

While following the trajectory of the caregiving career, I will also analyze how the factors associated with the caregiving career combine to enhance or mitigate stressors. The Stress Process Model (Lazarus & Folkman 1984; Pearlin 1999) posits "that caregiver adaptation is affected by multiple factors including caregiver background (individual and social factors), appraisal of stressors (i.e. magnitude of care, family functioning), and availability of coping resources." Using the concept of caregiving literacy, I will analyze the knowledge and skills CGs bring to the table prior to the start of their career, and how the evolution of this skillset influences their self-perceived levels of stress. Coping strategies can also be included in the acquisition of caregiving literacy. The thorough examination of the ADC's daily procedures allows for an analysis of the structural coping entities available to caregivers. Using this model, factors that significantly impact health and stress outcomes can be classified and targeted for interventions.

The Caregiving Career as a Case of Disrupted Identity

Using Becker's research theory of careers allows my analysis to explore the steps in the caregiving process, and how different moments have varying degrees of impact on the trajectory of social relationships. In his analysis of medical students (1961), Becker documented how these individuals "become" doctors, gradually assimilating to the medical field through their interactions with others. There are steps in the process of becoming a doctor, but it is not necessarily a linear process. There are certain moments of greater significance that alter the pathway to becoming a doctor more so than others; these moments of significance can quickly cause the individual to interact with their social environment differently.

Additionally, Diane Vaughan's work on how romantic relationships end (1987) describes how breakups are a process, and that the two people involved are rarely on the same page about how to proceed. Interestingly, she notes that there is always one person in the relationship who wants it to end (the initiator), while the other wants it to continue. At this point, the initiator dictates the relationship trajectory, and the other partner must always to adjust to these changes. In the caregiving context, this same process can happen between caregivers and care recipients. The recipient's condition is unpredictable, and throughout the course of their interactions the caregiver must continuously reorient themselves and their approach to the caregiving process based on the needs of the recipient. This may involve acquisition of new knowledge, use of additional social services, etc.

For example, many elders who have begun to experience physical ailments due to aging report "middle of the night problems," which are medical issues arising outside of their doctors' office hours but are not serious enough to call 911 (Walker et al. 2017). Minor cuts/abrasions, injuries that do not feature intense bleeding, or accidentally taking double dosage of medication would fall unto the category of middle of the night problems. In these cases CGs may be called upon for assistance, and due to their unpredictable nature the CG is more or less at the whims of the CR. This scenario presents two main implications: 1) the CG must become knowledgeable enough about the maintenance of these minor occurrences to be able to handle them at a moment's notice. Learning to patch up minor injuries or being familiar with how certain medications interact with each other is imperative. Additionally, the CG is constantly adjusting to the condition of the CR and must be ready and available at all times if they are to provide sufficient care.

Micro-Level Family Dynamics

First, I will examine participants' family units through the lens of the support offered by ADCs and the caregiver's perceived caregiving literacy. The ADC provides respite to the caregiver while also offering opportunities for social interaction for the care recipient, so ADC utilization would conceivably contribute to a less strained family unit in which the caregiver is not overly burdened and the care recipient is supervised and stimulated during the day. Assuming the family unit is satisfied with the performance of the ADC, their daily life should be more stable and manageable than it would be if they did not utilize these services. I will analyze the effect of the ADC on the caregivers' family unit stability by exploring occurrences and trends before and after they utilized this service. Regarding caregiving literacy, having a higher degree of this literacy conceivably allows the caregiver to have a more stable family unit. Being familiar with ways to cope with symptoms, knowing the best ways to interact with an IWD, and being able to manage social situations with the IWD make it easier to proceed through the caregiver career with fewer bumps along the way. My analysis will explore the degree to which strain and disorganization throughout the caregiving career is associated with caregiving literacy acquisition.

Pathways Into Adult Day Centers

Vital to this analysis is exploring the pathways through which family units come to utilize ADCs and the patterns of help seeking between informal and formal sources that brought them there. CGs may utilize many different sources of information throughout their caregiving career. Informal sources include family, acquaintances, etc., while formal sources include medical professionals. I will explore the link between these two sources of information and how a CG's place within the social structure, relative to formal and informal entities, influences their utilization (or non-utilization) of ADCs. This chapter is framed by a three-step model for understanding caregiving families of individuals with dementia.

Caregiving Literacy

Additionally, I use the term "caregiving literacy" to refer to the "know how" of being a caregiver. Ranking highly on the spectrum of caregiving literacy means that the individual has the holistic knowledge needed to properly care for someone; knowing the causes and symptoms of the disease and the best way to treat, maintain, and/or relieve the effects of this condition. Furthermore, an individual with high caregiving literacy has the capacity to navigate the social scripts involving interaction with the care recipient and the care recipient's interaction with others.

The internalization of caregiving literacy can develop from a variety of sources, including media portrayals, education, personal experiences, and the observation of others. I postulate that even people who do not have children have an adequate level of childcaregiving literacy given the greater public prevalence of childcare; we observe childcare within our own families, through media such as TV and movies, etc. However, elder caregiving literacy is not as readily acquired for a number of reasons: caregiving for elderly family members within the family unit is more rare than caring for children, it is less often portrayed in media, and much less of this care takes place in public spaces.

I will explore the pathways to acquire caregiving literacy by analyzing the sources of the individuals' knowledge for how to proceed effectively throughout the caregiving career. Did they utilize trial and error, use online resources, take classes, or gain knowledge by some other method? By inquiring about the caregivers' literacy, I can explore how this feeling of proficiency corresponds with ADC use and their perceptions of family unit stability.

While I see value in analyzing multiple types of care, my focus for this project will be on caregivers whose family members suffer from dementia. Because of the way that dementia impacts the cognitive ability of the care recipient, I am greatly interested in how families navigate the path of decision making for an adult who was formerly an independent actor.

Through this analysis, we can not only better understand the nature of the isolated task of caregiving, but also explore patterns in how disrupted family systems recalibrate themselves. How are previously well-understood scripts (e.g. those for interactions between a parent and child, for fulfilling one's role as a spouse, etc.) rewritten once the caregiving career commences and roles begin to evolve? How does a caregiver achieve a "new normal" and restabilize their family unit, if ever? In Kimberly's case, the younger adults in the family each had to take on new responsibilities to accommodate the deterioration of her parents' health. However, these tasks were not equally (or even systematically) distributed. Kimberly took on the bulk of the responsibilities while other family members had fewer tasks. Key to my analysis will be the role of ADCs in this process. I would like to observe the patterns that emerge for caregivers that utilize this form of support as opposed to those who do not. My goal is to track how these changes progress and the negotiations that take place within the family as the situation evolves.

Chapter 2: Data and Methods

This dissertation grows out one year of fieldwork I have conducted at an adult day center in the Central Texas. This center is under the umbrella of Midway, a nonprofit organization that offers support and resources to those undergoing early memory loss (who are referred to as "members"), their caregivers, and their families. There are 464 facilities in Texas classified as "day activity and health services," but Midway operates the only two in the Central Texas area (Texas Health and Human Services Commission 2018).

Midway offers a number of services: caregiver education and resources, classes for CGs to acquire practical skills in managing their CRs, early memory loss support, health equipment lending, peer-based computer classes for seniors, and ADCs.

ADULT DAY CENTERS

In general, there are three types of adult day centers: social, medical, and specialized (NADSA 2017).

- Social adult day centers provide an opportunity for interaction with other seniors, as well as nutritious meals. There is often recreation and some health-related activities
- Medical adult day centers provide social activities, but also have more thorough health and therapeutic services
- Specialized adult day centers only provide services to those with specific conditions, such as dementia or other developmental disabilities

Depending on the condition of the CR, they may be better suited for one type of ADC over another. For instance, individuals with serious cognitive impairment may not benefit from social ADCs because they cannot participate to the same degree as other members. Such a person would probably be best suited for a specialized ADC, where the staff has more specific training to cater to their circumstance. A medical ADC is probably the best option for a CR who has more physical disability than cognitive disability. They will be in an environment tailored to their bodily debility while still reaping the benefits of an enhanced social environment.

ADCs are the main program offered by Midway, and both of their facilities specialize in providing care to those suffering from early memory loss; all activities and social engagement opportunities are constructed with this in mind. The stated goals of their ADCs are to:

- Stabilize medical conditions and reduce hospitalizations
- Prevent secondary disabilities that result from excessive bed rest or inactivity
- Lead to improved ability to perform daily activities
- Increase self-esteem and dignity
- Increase verbal ability and mobility
- Elevate mood and improve behaviors
- Improve nutrition
- Provide opportunities for friendship and decrease the harmful effects of isolation and loneliness
- Be something to look forward to
- Foster a sense of belonging
- Create a feeling of belonging to a community

I spent 18 months volunteering at Summit, which is one of the ADCs operated by Midway. At Summit there are approximately 36 total members present at any given time, with a running wait list for anyone who is interested after a current member no longer attends. The reason for such a specific number of members is that the staff maintains an

8:1 member-to-employee ratio, which is mandated by the state. Summit features a full time staff of program and activities coordinators, nurses, and nurses' aides.

THE STRUCTURE AND DAILY ORGANIZATION OF SUMMIT

Program Director

Summit's program director is named Molly. As program director, she oversees the general operations of the facility and handles all administrative duties. The program coordinators (one at each ADC) are in charge of managing the day-to-day operations of the facility and are the head individuals in charge of all functions; the program coordinator approves all final decisions, and they are also in charge of hiring and firing people.

When potential members want to apply for a spot at Summit, Molly is their first point of contact. She handles all of the paperwork and visitations scheduling, and is also the main person who interviews the family and the member. All official business not related to activities is organized and channeled through the program director.

Activity Director

Summit's activity director is named Maya. The activity director is specifically in charge of coordinating and implementing the activities that the members engage in while they are at present. These activities include arts and crafts, movies, games, trivia, gardening, seasonal parties, music, reminiscence discussions, etc. These activities are designed to promote connectedness, competence, belonging, optimal functioning, and an improved quality of life.

Activities are not determined at random on a day-to-day basis: the activity director is responsible for creating a monthly calendar outlining a schedule for the upcoming month. These calendars are quite precise and measured down to the hour. Some activities are fairly standard and done often; for instance, it is not unusual for members to take a walk around the perimeter of the building at least once a day if the weather permits. Additionally, activities later in the day are fairly standard since many of the members have left for the day. Members who are the last to leave Summit settle into a routine of watching Jeopardy and then playing Wii bowling until close.

The activity director also schedules a few novel activities throughout the month. Many of these are based on volunteer participation. For instance, local musicians sometimes attend a few times a month to play songs for the members. Various organizations also send helpers to coordinate activities or play games; for instance, the partners and sponsors sometimes send their employees to interact with or play games with the members. On one occasion, I facilitated a trivia game as the members were split into teams, and each team was headed by a worker from the local hospital who had come by to help out for a few hours.

Nurses and Nursing Aides

Finally, Summit provides nursing services. The staff of each ADC features a registered nurse, a dietary consultant, and nursing aides. These nurses are primarily responsible for the more nuanced care of the members, such as assisting them when they go to the bathroom. The nurses and aides on staff are also available to administer any medications that the members need, and they give each member a health assessment every month. Upon admission into the ADC, each member is given a full medical assessment to ensure that the member's health is being monitored as accurately as possible. The member's primary physician must first approve any medication administered by nurses or aides.

Other People: Helpers and Volunteers

Helpers and volunteers are vital to the functioning of Summit. I designate between helpers and volunteers: helpers are those who are short-term, while volunteers are longer-term. Anyone from the community can help out, but they typically come from community organizations such as Girl and Boy Scouts, local schools, and workplace outreach (e.g. an company may send a few of their employees to assist for the day).

The most consistent form of help is during the summer, when local students come in while they are out of school. Some need community hours for school organizations, some are placed there through district summer work programs, and others simply come by to offer their time for free. Summertime is also a busy time for mother-daughter groups to offer their assistance. Having these sources of help is a great benefit to Summit because they can get ahead on tasks for later in the year. For instance, Maya often had summer helpers print out holiday activities for the members that would last for the rest of the year. With the extra assistance, she was able to set up Halloween, Thanksgiving, Christmas, and Valentine's Day activities months ahead of time

The long-term assistance comes from volunteers. Although also unpaid, volunteers consistently show up at scheduled times throughout the week. For instance, when I first began I volunteered at Summit three days every week. There were a few others who had consistent, multi day per week commitments to Summit. We mostly do on-demand tasks, such as helping out with whatever is scheduled that day. Typical tasks would be watering the plants, cleaning the offices, or playing games with the members. Due to the frequency of attendance, these volunteers tend to have a stronger rapport with the members than anyone else outside of the staff.

Other volunteers come in for more targeted reasons. For instance, a guitarist would go to Summit every Thursday afternoon to provide musical entertainment for the members. Another volunteer would show up once a week to do light exercises with them. Still another would bring therapy dogs to interact with the members. While this class of volunteer appeared more rarely than the other (like me), these individuals often brought a sense of excitement since they had a certain skill or specialization

Physical Description of Summit

Summit is located in a commercial area, surrounded by other businesses. It borders a park on one side and a neighborhood on the other, but the lot that contains Summit and the surrounding businesses had a very business-like feel. However, due to the painted and decorated windows and full garden behind the facility, Summit sticks out among the rest.

Summit is a single story building with a keypad-secured lock on all doors for security purposes. They have had more than one instance of members wandering out and into the parking lot. There are a few twists and turns in Summit, and from the outside it does not seem like there would be as many rooms inside as there actually are. Upon entering, there is an office to the right (where Molly works) and another larger office/stock room straight ahead, and between these two rooms is a short hallway that leads to the main room. This is where all activities happen, as well as the area where the members spend most of the day.

The main area features three long tables with chairs all around. During any crafts and other active periods, members are seated here. The table closest to the back of the room is unofficially called the “Men’s Table,” and the men (who are heavily outnumbered among members) have turned it into their own area. It’s often covered with car magazines, puzzle books, newspapers, and other things that the men use more than the women. The men rarely participate in crafts and activities, so this is their area for practically the entire day. There is also a smaller area featuring about 20 recliners and a few other chairs, where members can relax (and often fall asleep). If there is a more leisure-based activity, such as watching a movie, the members may be seated here.

In the far corner of the facility is the kitchen and storage area, featuring industrial ovens, refrigerators, freezers, washing machines, and sinks. Shelves line the walls with various supplies, mostly for cleaning and serving lunch. This area also has a large industrial door that rolls up, and this is where weekly supply deliveries are made. Next door to the kitchen area is Maya's office, which houses everything needed for daily activities. This office is perpetually messy for a variety of reasons, and is a high traffic area due to the nature of its contents. Whenever there is a transition throughout the day, staff and volunteers often have to switch out supplies in this office.

Bathrooms line the back wall of Summit. There are three of them, which is usually more than enough to service the entire population. In the corner of the facility there is the nurse's office, where all medical supplies and records are kept. I spent little time in this room, since I was typically busy doing other tasks. Finally, across from the nurse's office is the nap room. Often empty, this room had a few small bookshelves and a bed. The bed was rarely used, but when it was occupied it was usually by the same rotating cast of members. Staff tried to avoid letting the members sleep while at Summit, but sometimes it was unavoidable.

Daily Operation

The ADC is open from 7:00am – 5:30pm Monday-Friday; members can attend each hour every day or whatever combination of hours works for the family. ADC staff suggests that members attend as much as possible, and many of the members do indeed attend five days per week. Throughout my field observation, I never encountered a member who attended fewer than two days per week.

The members are served lunch every day at 12:30, along with two snacks. Lunch is served hot but often consists of pre-packaged meals that are heated in the oven prior to serving. The drinks are typically juice, milk, or water (other drinks such as coffee or tea are served occasionally, but this is usually a special occurrence and not served during scheduled meals). Snacks are served mid-morning and mid-afternoon, and vary in content; they typically consist of fruit, crackers, or some other food that is quick and easy to serve. Members are not forced to eat any of the food provided to them throughout the day, but the ADC staff is required to serve them.

Maya plans each and every day, down to the minute. If there are recurring volunteers coming that week they are added to the list automatically, and then she fills in the rest of the time as she sees fit. The list of things that fill the day seemed endless, as I observed so many different operations designed to keep the members busy: sing-alongs, movies, sports (altered to make them easier and safer, such as replacing a volleyball with a balloon), crafts of all kinds, trivia, walks to the park across the street, planting in the garden, board games, decorating the facility for holidays, and tea parties.

Transportation

There are two main ways that members are transported to and from their homes: Midway-provided buses or riding with family members. Based on the location of their residence, some members qualify for Midway’s door-to-door round-trip shuttle service, which is provided at no additional charge. Transportation may not be available for all members due to limited space on the buses and the current route, but a significant number of members still use this form of transportation. I recall being at the Summit on afternoons when the bus would arrive, and the number of members present would promptly be halved due to the number of people getting onto the bus. A staff member at the Summit typically drives the bus (anyone other than Maya or Molly).

METHODS

Grounded Theory, Coding, and Framework Construction

I utilized concepts of grounded theory to explore the issues that arose throughout my fieldwork and interviews, as illustrated by Charmaz (2006). This process involved constructing the framework through which I analyzed my data as I conducted interviews and volunteered at Summit. I began this study with one question: How does providing care for someone with dementia impact the family unit?

The rationale of approaching the study in this manner was to allow the most important themes to present themselves as organically as possible. My idea of what was important underwent a metamorphosis during my 18 months in the field. Since caregiving is such a multifaceted and transforming process, there were various realities portrayed by CGs and CRs that I needed to incorporate in my analysis.

Early on, I simply made observation at Midway events and Summit so I could grasp the responsibilities associated with the care of someone with dementia. This was the first stage of framework development. Beyond observation, it involved speaking with staff, learning the structure of the organization, and occasional interaction with members. As time progressed, I internalized the norms of the environment while beginning to interact with the members more. This allowed me to construct an embodied understanding of what it is like to be responsible for the management and wellbeing of someone suffering from early memory loss. After a few weeks of this, I began conducting interviews.

Prior to the start of the study I had a general interview guide that I had planned to use, but I updated it to reflect the observations I had made. For instance, initially I did not have any questions on the environmental aspects of caregiving. However, it became apparent to me that environmental factors are immensely important to the process: What kinds of locks are on the doors? How far is the bedroom from the bathroom? Are we sure that all of the essentials are downstairs so they are more accessible? I added questions reflecting such concepts.

All interviews were audio recorded with the consent of the interviewee. I utilized a semi-structured style, presenting general questions to guide the conversation while leaving ample opportunity for elaboration from the participant. Many times participants were eager to discuss topics more in-depth than I would have anticipated, making this style a useful technique. Additionally, by not forcing the interview to follow a rigid structure, I was able to take a deeper dive into poignant issues through unscripted follow-up questions.

As interviews were underway, I moved to the second stage of framework development. Each interview was transcribed verbatim within a week of its completion, and shortly after I would code the transcripts. Initially, I printed out redacted transcripts and marked important issues that would arise throughout the interview. By reviewing transcripts word-for-word and line-by-line I identified key points. These key points were compiled in an Excel spreadsheet. Examples of these key points are “emotions,” “visits to the doctor,” etc.

Following each interview, I reevaluated the relevant topics discussed and considered how they fit into a larger framework. In this way, the interviewees in this study unconsciously played a major role in the development of the overarching theme of the project. I then adjusted the general interview guide to reflect information gathered from the previous interviews. For example, I began breaking key points into more nuanced and descriptive chunks, such as breaking “visits to the doctor” into “initial consultation,” “emergency visits,” etc. Key points that reappeared in multiple interviews were given priority and combined to form themes, and smaller instances were framed in reference to these themes. By moving from incidents to themes, I was able to begin forming a clearer picture of the common threads linking individual CG's experiences. As these more descriptive tags we identified, I reflected these changes in my master document containing the themes.

Finally, as strong trends began to solidify I developed defined themes that make up the overall framework of the study. This involved reducing tags to the most nuanced level possible, then constructing a concept that linked them together. General patterns began to form among the narratives from the participants' narratives, and through this I was able to insert different individuals' experiences into an overarching framework. For example, regarding the way CGs interact with doctors, I had multiple tags insinuating that CGs were not only getting their medical advice from medical professionals. Despite interacting with them regularly, I also had tags suggesting that CGs trusted nonprofessional advice such as "coping advice from acquaintances" and "online research," and these tags persisted long after the CR was engaged in regular doctor's visits. Through this process I realized that there was a nonlinear process at hand: CGs were not moving from nonprofessional to professional advice regarding caregiving, but were simply incorporating professional advice into the system that had already been established. This realization ultimately helped me develop the *Echoed Help-Seeking* framework as discussed in Chapter 4.

Field Observation

Field notes from volunteering at Summit followed a similar trajectory. Each day, I typed notes recalling my observations from that day as soon as possible once I left Summit. For the first couple of months, I made general observations and attempted to observe as much as possible. Once I developed a strong understanding of the social arena, I began reviewing my field notes again and forming ideas about the way the staff and organization disseminated care.

Eventually life became routine at Summit. I became a familiar face, even to the members who were suffering from early memory loss, and much of the staff viewed me as one of their own. Although new things happened every day, when life at Summit became more routine I was able to focus on more nuanced aspects of the organization. For instance, after I had been at Summit for over a year I began to pay special attention to the way staff spoke to members. Not just in their tone, but in the exact words they used. Since I had made such long-term observations of the space, I was confident that I could begin focusing my attention on more intricate levels of Summit. My field notes became more focused as I switched to this strategy, and coupled with my more general early observations, painted a holistic picture of the organization.

My time volunteering at Summit was the most important aspect of forming my research objectives and frameworks. While literature review and interviews were crucial, my fieldwork provided my reference point for what interacting with an individual with dementia is like. I was present to observe all aspects of care: social interaction, negotiation, feeding, bathroom use, conflict resolution, and planning. I was able to see the behind-the-scenes preparation and labor necessary to manage individuals with cognitive disabilities, and I shaped my interview guide with these processes in mind.

Having 18 months of interaction with members and staff allowed me to gain a comprehensive understanding of care from a personal and institutional level. Additionally, I was able to cross reference information I gained through interviews with observations I made in the field. For instance, if a participant spoke of their CR's improving adjustment to the atmosphere at Summit, I paid special attention to that process during my volunteer hours. This practice also helped ensure that the study was as thorough as possible and that no poignant questions or themes were left unanalyzed. I stayed up to date with relevant processes by consistently rereading field notes and interview transcripts throughout my fieldwork.

What Does "Caregiver" Mean?

One issue associated with caregiving research is that there is not one strict, standard definition of "caregiver." Although medical professionals and entities may attempt to define it, the subjective definition of the term and how it is used can have varying implications on the micro level, making it an important research focus (Zarit & Reamy 2012).

For the purposes of this study, I define caregiver as "anyone who provides support or assistance with tasks of day-to-day living to maintain the wellbeing of an individual who can no longer conduct those tasks on their own due to old age, injury, illness, or any other external circumstances" These tasks can entail a variety of responsibilities:

- Household tasks such as cooking, cleaning, and mowing the lawn
- Tasks that require actions outside of the home, such as grocery shopping and retrieving medication from a pharmacy
- Personal hygiene tasks, such as bathing or assisting in the bathroom
- Interpersonal activities, such as conversation, leisure activities, etc.

In this study, to be classified as a caregiver one must perform one or multiple of these functions for someone who can no longer fulfill them. For instance, in a vacuum, conversation is not a form of caregiving. But if an elderly person can no longer leave the house to enjoy the company of their friends, a CG may visit occasionally to provide social engagement. This qualifies as caregiving, since a lack of social engagement can have detrimental effects on one's wellbeing.

While there are some individuals in the interview sample who never explicitly referred to themselves as a caregiver, the tasks they performed and responsibilities they were given fit into the definition for the purposes of this study.

Interviewing: the Process and the Participants

All participants who were current or former ADC users were encountered through Summit. Molly introduced me to most of them; although I would speak to family of members relatively often, I never initiated an interview. Molly would inquire about an individual's willingness to speak to me, and if they were comfortable with the prospect then she exchanged our contact information. This process was to ensure that no one felt pressured or compelled to participate if they did not want to. Since they all had much more rapport with Molly, she would approach them first, ensuring them that they were under no obligation to provide an interview if they did not want to.

The remaining interviews were mostly obtained through a snowball sample of individuals I met through community events and social ties. The large majority of these interviews took place after I had already completed a number of interviews with Summit users. I met some participants at support groups and other similar community meetings. Early on in my research I reached out to community organizations that provided eldercare support groups, and a few of them were kind enough to allow me to sit in on the meetings. This was beneficial in two ways: first, I was able to hear people's stories, which helped me frame my own research questions and themes. Additionally, I formed enough of a rapport with a few of the support group participants to where they offered to participate in my research.

I encountered a number of non-ADC participants through community organizations and events. For instance, while attending a talk at UT Austin, I met a community organizer who was interested in making society more senior-friendly. After chatting with her following the talk, she put me in contact with a woman who did similar work through her self-run website, which offered resources for caregivers. And through this woman I met another acquaintance of hers, who had recently began caring for her parent.

While I was able to obtain great data, the inherent issue with the methods I utilized is that it is a small and relatively homogeneous sample. Since all of my ADC participants used the same facility, and many of my non-ADC participants were the result of a snowball sample, I was not able to obtain the diverse sample I had hoped for. However, the information that I was able to gather is valuable in that it sheds light on the caregiving experiences of a particular demographic, and I was able to analyze the differences among this group despite their many similarities. Further discussion of the study's weaknesses is discussed in the Conclusion (Chapter 7).

Interviews typically took place at the residence of the CG. They were mostly happy to bring me into their homes and conduct interviews in their own private spaces. 11 of my interviews were conducted here, and the remainder was at restaurants, coffee houses, and bookstores. As mentioned above, the interview format was open ended, and although I asked guiding questions the participants freely spoke about whatever topics were of interest or significance to them. Interviews were truly more like a conversation than an interrogation, and I found that in general participants were very willing to share detailed aspects of their lives. Most interviews lasted about 90 minutes. There were a couple of outliers (one was only 35, another was close to three hours), but all were completed in one sitting and recorded fully.

Although the semi-structured nature of the interviews allowed for flexibility in the topics discussed, I focused on a few main themes as guiding questions in each interview. These general themes are displayed in Table 4. I asked more nuanced follow up questions based on the specific circumstances of the interviewee and the key points I had developed from field observation and other interviews.

1	Early life relationship between CG and CR (pre-caregiving)
2	The physical/cognitive decline of the CR that left them with the need for care
3	Roles the CG has had to take on to effectively provide care
4	Specific ways the CR's condition affects their lives, behavior, etc.
5	Interactions with doctors and other medical professionals
6	External services or other social support (friends, acquaintances, etc.)
7	How relationships within the family unit and with other individuals are affected by caregiving
8	Outlook on the future as a caregiver

Table 4: General Themes in Caregiver Interviews

Three sets of participants were closely related. Ken and Jillian are brother and sister and care for their mother, who is a Summit attendee. They were interviewed separately, and I actually did not know they were related until after the second interview. Randy and Susan are married, and together they care for Randy's mother, who lives with them and also attends Summit. Finally, Sherry and Jermaine are married. Their classification is interesting: because each of them has health issues, they are actually informal caregivers for each other. They are very close to their adult children, who help them with daily activities and finances, but during the day their children are at work. At this point, Sherry and Jermaine monitor each other's health. Sherry has greater disability than Jermaine, so she attends Summit a few days per week. Jermaine does not attend. The Randy/Susan and Sherry/Jermaine interviews were conducted in the home with both members of the couple present.

Demographic Characteristics of Interview Participants

All individuals included in this study have been given pseudonyms, and information that may lead to the discovery of their identities has been removed from the manuscript. While characteristics such as age and gender are as accurate as possible, such information on its own does not reveal identifying information about the participants.

Relevant demographic information of interview participants is illustrated in Table 5 below. All participants are from the Central Texas area, and all who utilize ADCs had used Summit. The majority of the sample (73.7%) identify as female. This reflects the higher representation of women as caregivers in the U.S., although this sample is more dramatically overrepresented. Ten of the 19 respondents were current or former ADC users, while the other nine had not previously used ADCs.

Additionally, most of the sample identifies as white. This trend was unsurprising to me for two reasons: 1) the areas where both of Midway's ADCs are located are predominantly white, so the target population is likely to reflect that trend, and 2) the network I used to establish a snowball sample began with individuals who identify as white. While this does indeed present a fairly homogeneous sample, my rationale for continuing with a mostly white non-ADC sample was that I wanted it to reflect the racial/ethnic characteristics of the ADC respondents. While it is impossible to find exact parallels, maintaining general similarities in race/ethnicity between the two groups can make results more generalizable.

As expected, the entire sample is on the older end of the age spectrum. Of the respondents who disclosed this information only four were 50 or younger, while six were 65+. The older respondents tended to be spousal caregivers, while younger ones were more likely to be parental caregivers.

Overall the sample is very well educated. Of those who disclosed their educational attainment, 93.8% had degrees or certifications beyond high school. Similar to the homogeneity issues in race/ethnicity, I actively chose not to pursue a more diverse educational sample among non-ADC users to keep it as similar as possible to the ADC sample. As mentioned above, most of the non-ADC interviews took place after I had already started interviewing Summit users, and I noticed that individuals using Summit were an overall highly educated group. Thus, I sought to pursue a non-ADC sample that reflected this trend.

42.1% of respondents chose not to disclose their income. Of those who did disclose this information, no family unit reported bringing in $50,000 or less. This correlates highly with the educational attainment patterns (a highly educated sample is also a high income sample). While roughly 1/3 of the sample is retired, many of the employed CGs had occupations that allowed a degree of flexibility for providing care. For instance, all have salaried jobs that come with more benefits than wage labor.

Name	Gender	Age	Race/ Ethnicity	Caring for	ADC User?	Education*	Income**	Occupation
April	Female	60	Black/AA	Mother	Yes	SC/AD	51-100	Program specialist
Brandi	Female	48	Hisp/Lat	Father	No	Bachelor's	51-100	Retired criminal justice
Chelsea	Female	56	Hisp/Lat	Mother and Husband	No	Bachelor's	n/a	Website management
Christy	Female	58	White/C	Father	No	Bachelor's	n/a	n/a
Diana	Female	67	White/C	Mother	No	Adv. Degree	51-100	University faculty
Jamie	Female	67	White/C	Mother and Father	No	Adv. Degree	51-100	Clinical nursing instructor
Jermaine	Male	79	White/C	Wife	Yes	Bachelor's	51-100	Retired
Jillian	Female	43	Hisp/Lat	Mother	Yes	Bachelor's	n/a	Engineer
Katharine	Female	64	White/C	Mother	No	Adv. Degree	51-100	Academic staff
Ken	Male	46	Hisp/Lat	Mother	Yes	SC/AD	n/a	IT specialist
Kimberly	Female	56	White/C	Mother and Father	No	Adv. Degree	101-150	Retired educator
LaToya	Female	41	White/C	Mother	No	Bachelor's	n/a	Student
Lisa	Female	n/a	n/a	Mother	Yes	n/a	n/a	Retired
Randy	Male	n/a	n/a	Mother	Yes	n/a	n/a	Retired
Roberto	Male	74	White/C	Wife	Yes (former)	Bachelor's	51-100	Retired
Russell	Male	53	Asian	Mother	Yes	Adv. Degree	151-200	Self-employed
Sherry	Female	79	White/C	Husband	No	Bachelor's	51-100	Retired
Susan	Female	n/a	n/a	Mother-in-Law	Yes	n/a	n/a	n/a
Tina	Female	74	White/C	Husband	Yes	HS	51-100	Unemployed

Table 5: Demographic Characteristics of Individual Interview Participants
*SC/AD = some college or associate's degree; Adv. degree = advanced degree
**Household income measured in thousands of dollars, USD

Gender	
Male	5
Female	14
Age (in years)	
41-45	2
46-50	2
51-55	1
56-60	4
61-65	1
66-70	2
71-75	2
76-80	2
No answer	3
Race/Ethnicity	
Asian American	1
Black/African American	1
Hispanic/Latino	4
White/Caucasian	10
Other/no answer	3
Caring for	
Father	4
Mother	12
Spouse	4
In-law	1
CGs with multiple CRs	3
ADC user (current or former)	
Yes	10
No	9
Highest Educational Attainment	
High School	1
Some college/associate's degree	2
Bachelor's degree	8
Advanced degree	5
No answer	3
Income (in thousands, USD)	
0-50	0
51-100	9
101-150	1
151-200	1
No answer	8

Table 6: Cumulative Demographic Characteristics of Interview Participants

Drawing Conclusions: ADC vs. non-ADC Population

In general, I was able to use interview data from all respondents to draw conclusions about the caregiver career. However, due to the significant split of ADC vs. non-ADC participants, some discretion was made at certain points throughout the study. For example, in Chapter 6 (Summit services), only interview data from the 10-person ADC sample was used to draw conclusions. Since the other half of the sample had no experience with ADC services, their narratives were not included in the analysis.

Conversely, my fieldwork at Summit helped not just with ADC sample, but with the non-ADC sample as well. On the surface it may seem like field observations at Summit would not be relevant to drawing conclusions about CGs who do not use ADCs, but my observations at summit went far beyond the institutional aspect. As mentioned above, I also used my time at Summit to observe the responsibilities and knowledge needed to properly accommodate an individual with dementia. Thus, the 18 months I spent at Summit allowed me to both have a more nuanced understanding of care (regardless of ADC status) and ask better, more significant questions during interviews with all respondents.

REFLEXIVITY

I recognize that a scholar's identity has the potential to influence the way they are perceived and the information they are able to obtain throughout the course of their research. In general, I do not believe my identity had a significant impact on the way my research was conducted or analyzed or the way respondents interacted with me.

An interesting observation is that the vast majority of members at Summit perceived that I was much younger than I really am. Nearly every day someone asked me what high school I went to, although this did not impact the way I was able to make observations while volunteering. Many of the members would compare me to their grandchildren (or great-grandchildren) since they assumed that we were approximately the same age.

During interviews, I believe my identity initially surprised a few people; many did not expect to see a younger black person ringing their doorbells when I showed up at their homes. Many of the respondents from the ADC sample had met me already prior to our interview, so we had already built a degree of rapport. However, especially in the non-ADC sample, our interaction prior to meeting for the interview was strictly electronic or over the phone. In one instance, I showed up to a respondent's office for an interview at the exact time we had planned to meet, and I was met with a very confused stare, and they assumed that I was lost. When I stated who I was looking for, they nodded and confirmed that I was in the right place, still looking flustered. When I introduced myself, a wave of recognition flashed across their face and they finally allowed me in. By my perception, I believe they simply expected a different person to walk in, and it did not even register that I was the interviewer when I showed up. Despite this, I never felt as though any respondents were more guarded than usual based on who they were speaking to; while they were initially surprised, all of them shared freely and often revealed very personal details about their lives and the difficulties associated with care.

While I went into the study with a grounded theory approach, I did have my own preconceived notions of care. My grandmother suffered from dementia for five years before her death, and although I did not live in the same city as she did I experienced care from afar. My parents and other family members provided unpaid, informal care for the duration of her illness. Based on this, I came into the study with an idea of how dementia care looks, although it was only from my family's frame of reference. With this in mind, I attempted to put this aside and build my themes and frameworks from the ground up, based only on observations from the field. This way, I could construct a representative set of themes directly from the data I was observing, leaving my own perceptions out of it.

However, I believe my experience with caregiving helped me get much richer data than I could have otherwise. In my experience, many CGs do not speak freely to strangers about their care responsibilities. With my experiences in tow, I was able to build instant rapport with many people who I had never met before. Although I was not a primary caregiver, many CGs noted how they felt they could talk to me because I "get it," and that because I had been so close to my grandmother before her death I would understand the emotional turmoil involved in the process. Indeed, many interviewees would dive into narratives about their care experiences without feeling the need to preface the story with extra details. Being someone who was so close to dementia care prior to my study, I was able to relate to respondents in a way that made them more comfortable sharing intimate, and often painful, aspects of their lives.

Chapter 3: Family Dynamics of Care

WHAT MICRO LEVEL FAMILY DYNAMICS EXIST IN CARE?

Before diving into caregiving literacy (the holistic knowledge needed to properly care for someone), pathways into ADCs, and the ways that Summit specifically caters to its members, I will explain the dynamics of a caregiving unit. These are groups of people, related in various ways, who come together in hopes of providing care to a person in a very serious and volatile situation. The way these groups and individual approach care differs, but there are patterns that can be outlined. In this context, "care" refers to any non-professional responsibilities that maintain the wellbeing of the CR. In this chapter, I will explore the micro-level events, interactions, and emotions that go into the caregiving process. The following is largely descriptive, but understanding how CGs view their caregiving careers, in their own words, is imperative for analyzing the subsequent chapters.

Personal Outlooks on Providing Care

It seems like a straightforward question, but why do people provide care? To be honest, many of the CGs I interviewed never gave a straightforward answer to the question. Some people may not be able to pinpoint why they do it at all. The main reason CGs cited for providing care was simply that they loved the CR and wanted to make sure that they were well taken care of. This may be due to unconscious loyalty or devotion to that person, but it is also shaped by the cultural ideology that person is born into. Cultural ideologies (i.e. how an individual's beliefs or culture shape their values and/or actions), such as familism, also strongly influence why an individual would provide care. Although this may be seen as a group characteristic, it can subconsciously influence individual outlooks on the salience of the caregiving career. Familism, which is the idea that the needs of the family unit are more important than the needs of any individual member of the group, still exists in current conceptions of family caregiving, although the context may be changing (Mendez-Luck et al. 2016).

Familism, however, is a spectrum and not a dichotomy. While each person in the sample feels some degree of familial obligation to the CR, some go to greater lengths to provide this care than others do. While many caregivers no longer give all of their time selflessly to the cause of care, there are still cultural obligations to assist in some way. Familistic tendencies may be beneficial to those in need of care because it creates a supply of available caregivers within the family, but for those providing care the benefits are not as apparent. While those who value the role may receive some benefits from it, prioritizing the needs of the CR over one's self is associated with "social isolation, financial hardships, and changes in living arrangements," partially due to unstained support from others within the family network (Mendez-Luck et al. 2016).

Some adult child CGs may provide care based on social exchange theory, which posits that care provision "is an act of reciprocation resulting from the fact that intergenerational relationships serve as channels for exchanges of resources and power" (Lan 2002). Children may provide care to parents as a sort of payback for the parents raising them, or may internalize this idea through socialization and social pressure. This is a collective ideology, in which certain egoist actions may be seen as disruptive to social harmony (Burleson 2003). In spousal care, one may feel that it is their duty to nurture their partner for better or for worse. Regardless of the specific reasoning behind their actions, each CG I spoke with reflected a scope of familism.

In some cases, CGs step up to provide care because they feel that no one else will do it. Kimberly, who retired early to provide care, was driven to her decision partially from surveying the situations and realizing that no one else could provide care the way she could.

> About five years ago I realized that if somebody didn’t step in and become more active in their healthcare that it could be catastrophic and impact a lot of other people as well. It [caregiving] wasn’t really an option for either of my sisters, they each live over a thousand miles away. It was me. So that’s how I ended up in that situation. And I did some checking on my own, and decided that I was eligible for retirement … At that point, if I took it then I could help facilitate what was really needing to happen in terms of their healthcare. So that’s kind of how I fell into it.

Katharine, who provides care for her mother, is the only person stateside who can provide care. Her mother’s previous husbands have passed away and her only sibling is too far away. “I'm stuck. I have no choice. My brother lives in Asia and he doesn't have to deal with it at all, besides having to listen to me complain and reading my grouchy emails. He has no responsibility.”

Brandi is in a similar situation, and she commented on how others outside of the household perceive her actions: “People say, for instance, ‘Oh you’re so selfless for doing this!’ No, not really. It’s not that, please don’t put me on some sort of pedestal. Because I have no choice.” Brandi has a sister, but she is unwilling to assist in the day-to-day aspects of care that their father requires. If Brandi does not engage in the care responsibilities she has taken on, her father would be forced into a nursing home. “Well, of course I have a choice, but the choices, they both suck. Do you put your parent away?”

Randy, who is assisted in the care for his mother by his wife Susan, also has two siblings who live in another city. Despite being much closer to them, they never helped with any care responsibilities. When Randy’s father died, he and Susan moved his mother into an unused bedroom in their house. Randy elaborated during our interview: “It’s a little frustrating too. I've got two sisters that lived five minutes away from my parents. And we would not see them.” Susan seconded his statement: “We haven't heard from them since we moved [Randy’s mother] up here. Well, even before the move, we'd only see them maybe at Christmas.”

“When they wanted something. When they wanted something we'd hear from them,” Randy said somberly.

Interacting with the Care Recipient

Providing care is an intensely personal responsibility, especially if the CR is a family member. While interaction is key to most social relationships, in the context of dementia the caregiving dyad may not be able to rely on traditional social scripts. Therefore, dementia CGs often modify the way they approach the CR. While their history together matters, the CR undergoes unpredictable and often frequent personality and mood changes that may radically shift the dynamic. This is referred to as *biographical disruption*, which is “the way illness disrupts the structures and meanings of ill people’s daily lives and activities as well as their relationships with other” (Barken 2014). CGs may be forced to reinterpret the past, present, and future to maintain a purposeful relationship with the CR. For example, the CG may have to redefine what a “good” relationship is; while they may have been able to bond with the individual prior to dementia over their shared love of cycling, they must rework their relationship in some way when the CR can no longer ride bikes or even talk about cycling anymore.

A common difficult adjustment CGs must make is recognizing that the CR is no longer the person they used to be, and that this change is most likely permanent. Despite an extensive past, this requires a reinterpretation of both the present and the future. Russell spoke of the painful process of realizing that his mother’s problematic behaviors were his new reality:

> It gets to be a real nuisance. If I'm ever in a hurry it drives me crazy. There's no way to hurry her, she has her own pace of doing things. The incontinence is a big

> thing, she's had lots of accidents, which is why I have to live in a house that doesn't have carpet. Bed pads, diapers, it's an ongoing thing.

Russell admits that coming to terms with these actions is more challenging because of their extensive history together.

> Behaviorally, I think it's harder for family members because I knew her when she wasn't this way. She'll do these highly ridiculous things, and I get so mad, saying, “Don't you know you're not supposed to do that? Why are you doing that?” It's like even though I fully comprehend what is going on, or not going on, in her head, it still bugs me because it's so obvious...I've known her for her whole life and she knows not to do this, and she does it. That part is really hard to adjust to, and it still crops up every now and then, I'm like, “I can't believe she did that.”

He has had to come to terms with the fact that although he remembers his mother as a strong and competent woman, she now requires near-constant surveillance.

> If I lie down to take a nap and I hear her messing with the microwave I've got to jump up and go take care of it. So it's the vigilance factor that's always there. That's what happened last week. One day I forgot to lock the door. She got out and went for a long walk, and she fell down and injured herself. You can still see the wounds, it's been a week. Exactly one week ago it happened. Luckily she healed and didn't break anything. It would've been really bad.

Lisa, who is one of multiple siblings, spoke about how each person in the family has had varying success in their attempt to come to terms with their mother’s cognitive decline.

> My brother, the one who lives out west, and I were never judgmental of her. Whenever she asked a question five times, we’d give her the same answer every time. We never made her feel like she was stupid. I love my sister to death but she has an intolerance for that kind of stuff. It’s just not something she can deal with. She understands her limitations, so she doesn’t try…she really tries hard to keep her mouth shut. Keeping that inner voice from speaking out.

Lisa recounts the previous statement with a laugh. Despite these efforts, their mother is aware that her children perceive her differently.

> She's always afraid of what my sister is going to say. And my other brother, he tries to treat her as though she's a child. And while I have to do everything for her as if she's a toddler, I don't treat her as if she's a toddler. My brother has a tendency to because he doesn't know how else to do it. And the other one that lives here just disconnects altogether. He cannot understand and deal with the fact that his mother is declining and sometimes doesn't know who he is.

Even though their mother has been diagnosed with dementia and all of the siblings understand the trajectory of the disease, they still have difficulty coping with the situation in everyday life. Lisa tells a story of a previous summer vacation to illustrate her point:

> A good example is when we were on our way to Colorado one summer for vacation. By brother and I, all seven of us went together. We were at the hotel and I was bringing her down for breakfast, and he, her youngest son, was sitting there. And she came up to me, within his hearing, and said, "Who is that?" I said, "That's your son."
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> "Oh, wow, I didn't know he was going to be here," she says. And he got mad about it, he got upset. And I'm like, 'Really? She doesn't have a choice in this. This isn't something that she can choose. She's not saying this because she's mad at you. She doesn't know. You don't interact with her a lot. When you're over here you hang outside with my husband. Or you hang out in the kitchen, and you don't sit down next to her and talk to her.'
>
> Whereas my husband and I, one of us is always sitting here watching TV with her. Not all the time, but most of the time we take her with us whenever we go places. We take her out to supper, we do all kinds of stuff with her. And if you don't do that, she's not going to engage with you because she loses those connections. And she loses them more and more as you go further down this road. She has a good relationship with me, she has a good relationship with her son up out west. She gets excited when we go up to visit. But as far as anybody else is concerned… Yeah, it's good to be around them, but they don't engage with her so she doesn't have that bond with them.

Although all of the children experienced a biographical disruption with their mother, some, such as Lisa and one of her brothers, found it easier to reinterpret their present relationship with her and accept her condition.

Jamie recognizes the biographical disruption she's experienced with her mother, but she admits that it is still difficult for her to endure the struggles that come along with the dementia symptoms. Their pasts are intrinsically linked, but their current modes of interaction are still disjointed:

> I know that my life is all tangled up with Mother's life. Their memories are all tangled up with mine, and it's difficult to maintain boundaries. Mother will ask if I remember something, and even if I say yes, she'll go and tell the story again. Even though I just said that I remember that. And it takes her so long to tell a story. It's so involved and filled with extraneous details.
>
> I'm like, "Where are we going with this?" I ask her a yes or no question and there's a whole story involved with it. "Did you get a hold of the bank?" She says, "Well, I called them and I tried to get through the menu, and you know that's just so involved. And I couldn't hear what they were talking about. I finally just kept pressing buttons but I couldn't understand them." And I'm just sitting there like, "Did you call the bank? Yes or no?" All of these extraneous, useless details. I just want her to answer the question, but I understand. Her brain does not work like that anymore.
>
> Her brain cannot organize just to answer the question, and that is because she has memory impairment. She's not able to organize her thoughts in a coherent manner. I get all of that. But it doesn't make it easier to deal with when I have other things that I need to do, and we were just involved in a 10-minute story.

Although Jamie's words indicate that she understands her mother's condition, her reaction to these behaviors suggest that she has difficulty internalizing that idea and approaching conversations with her mother accordingly.

If the CR has trouble communicating, such as in Jamie's mother's case, the CG may have difficulties deciphering their wants and needs. This can have detrimental effects not only on the CG-CR relationship, but also on the CR's wellbeing. As communication diminishes, the CG's idea of the CR's preferences and values may become skewed. Research by Reamy et al. (2013) suggests that CGs "increasingly de-emphasize the importance of values held" by CRs. Part of this trend may be the result of CGs actively creating emotional distance between themselves and their CRs as an adaptive strategy; if providing dementia care for someone they love is painful, they may intentionally close themselves off. Lisa's brother, who seems to disconnect from the situation as a coping mechanism, best exemplifies this notion.

Multiple CGs spoke of negative mood changes in the CR following the onset of dementia symptoms. While affecting memory and motor skills, dementia is also notoriously transformative to the IWD's personality. This often manifests as defiance, aggression, and anger. CGs, especially those who have not encountered these emotions regularly in their relationship with the CG, may need a significant adjustment period to adapt to this new biographical present, while also preparing for further transformations that may materialize in the future.

Kimberly recalls her mother's behavior and how it varied based on who she was interacting with. "She was a passive defiant…with everyone except me. Me and my sister, we got the aggressive defiant. But we were in that primary care roles." Kimberly's mother would refuse to take medications, engage in socializing events, and alter her negative health behaviors. To others she would simply decline, but when interacting with Kimberly the interactions were more hostile. Despite their shared biographical past, Kimberly received the brunt of her mother's conniptions.

Tina's husband also exhibited signs of staunch defiance.

> He used to argue a lot, up until three months ago. He'd say, "There's nothing wrong with me. Nothing's wrong with me. The doctors just want our money." He still won't admit it. But the last three months he's gotten real quiet. He must know.

In Tina's estimation, her husband's defiance was partially an attempt to reject the pervasiveness of his illness, but he had quietly accepted his condition.

Chelsea's mother, typically an energetic but sweet woman, descended into frequent mood swings at the onset of her dementia. Chelsea was initially shocked at this turn of events:

> My mother at this point was really snippy, very obviously stressed, because she was very short. Oh my gosh, I saw this side of her that I had not seen before, it was not pretty. My dad was always very gentle and loving, and so was my mom, but that's why I had never seen this other side.

While dealing with early memory loss, Chelsea's mother was also struggling with her husband's recent cancer diagnosis, which may have exacerbated the changes.

> It got so bad for my mom coping with the responsibility and the fact that her husband had cancer…when you hear cancer it's very scary, and you immediately think that he's going to die. Death was never talked about in the family. "Oh, don't say the word!" kind of thing.

While CRs often dispute and defy their CGs, there are also instances where they are very cooperative and thankful. Some CRs become docile instead of aggressive, and even though they can no longer communicate in the ways they used to they may still attempt to maintain harmony in their relationships. Susan spoke about how the transition to becoming a CG was made easier by her mother-in-law's willingness to oblige:

> She actually, to her credit, has been, and was, good about accepting what's going on. She didn't scream and yell about losing her independence. She was also very good in the fact that she had her will, her directives, all of that stuff taken care of as well.

Such a relationship made the transition to the caregiving career easier for Susan and her Randy. Randy's mother never attempted to leave the home, was always willing to take her prescribed medications, and maintained her even disposition from the first day she moved in with them.

In some cases the personality changes that come along with dementia may be welcomed by the CG. Although their biographical past may be intertwined, not all relatives are fully pleased with the dispositions and actions of their loved ones throughout life. If dementia represses some of the more controversial aspects of the CR's personality, it can lead to a more amicable existence. Lisa spoke of her mother's sometimes-abrasive personality early in life and how dementia changed her: "She's become quite a bit nicer. She used to be…" Looking away, Lisa took a long pause before continuing.

> She used to have a mean streak in her. Where she could be very rude to people, just real passive aggressive kind of personality. You know, she used to…she used to speak negatively about my appearance. This is what I am, okay? But she's now at the point in her life where all of that is gone. The minutia is gone. It weeded itself out of there, so now she's at a more grateful stage.

Difficulties Managing the Care Recipient

One of the issues associated with aging is the shrinking of social networks. Older adults may have fewer and less meaningful social interactions if they are homebound or are unable to drive a car or organize other means of transportation; these effects can be exacerbated by dementia symptoms. Kimberly recalled how her parents' lives changed as they aged and began suffering from early memory loss:

> When my dad was still alive they started losing a lot of their other friends. When he did give up his drive's license and Mom wasn't comfortable driving, they just started pulling in. They'd sit in their chair and watch TV. Maybe sleep. And so they would decrease those interactions, which I think became a downward spiral. Mom would go through cycles after Dad died of being active.

An aspect of this trend was the physical health of her parents. Additionally, while suffering from a shrinking social circle due to mortality, Kimberly felt as though her parents were also closing themselves off due to their cognitive decline. In the early stages, when both were aware of their conditions, they may have chosen to remain homebound more often instead of engaging in social activities and risking others discovering their ailments. When this occurs, CGs and other family members may feel pressured to pick up the slack for the CR's lack of outside contact.

Jermaine and Sherry spoke of how their conditions restricted social activities as well. Jermaine has a few physical ailments that prevent him from moving as well as he would like to, while Sherry has issues with her memory, cognition, and eyesight. Jermaine commented:

> We don't have the means to have much of a social life… Most people start out their social life through their work or their church. Unfortunately they don't have our denomination around here. We found a Methodist church that looks like we might be interested in it.

> "We don't have a social life," Sherry chimed in with a laugh.
>
> "That's a wanting in our lives," Jermaine continued.
>
> We've been here for about three years, three and a half. We're not able to...well I shouldn't say we're not able. We are able, but we haven't figured out or we don't have the will yet to go out and find friends who are around our age with the same similar interests.

"We used to play bridge, that was our thing," said Sherry. "And I can't play bridge anymore because I can't see enough, and I don't remember well enough to play and be a good partner."

At times, aging individuals may insist on continuing to engage in activities or roles they can no longer perform as a way of maintaining a sense of self and independence (Heid et al. 2016). This tendency may become more prominent as the CR's condition worsens. Although they cannot execute the same tasks they used to, CRs may attempt to maintain those roles. Additionally, they may rebuff concerns about their diminished abilities.

Roberto spoke about how his wife continued to challenge the assertion that she could no longer work. She was laid off by her employer, and the company tried to make the transition as easy as possible:

> They were very kind, they gave her five month's severance pay. They gave her support. I think what finally happened is her behavior deteriorated to the level where she was viewed as a threat. So they gave her a nice, easy way out. That's what happened.

Despite this, Roberto's wife remained insubmissive:

> One of the things you find with any dementia is denial. 'There's nothing wrong with me. I'll be fine.' But at some point, I don't remember when, she realized things weren't the way they should be. I think part of it was her ability to cope with things. Any change, anything new, was extremely threatening to her. So I think at some point along the way she realized things weren't right. She didn't know what the problems were, but she lost the ability to get that far. She realized that things were not right. And she became more passive when that happened.

Tina's husband was always an active man, both occupationally and recreationally. She found that even though he no longer had the same abilities, he would attempt to engage in the same activities he had done his entire life. Tina had to go to great lengths to accommodate his actions:

> Up until this time last year he was riding his bike every day, and my son put a GPS tracker on it. And I would just sit here with my phone, and he started getting lost more and it became dangerous. I could restrict him from going out in 100-degree weather, so I locked his bike up. It was when he could no longer exercise,

> he can no longer ride a bike, and hasn't driven a car in over a year, naturally. So he's bored here, real bored.

This development had a clear effect on his health, as he gained significant weight following the bike incident. After this method of exercise and recreation was taken away, Tina's husband tried to entertain himself by doing things around the house. "Being an engineer, he would take the door handle off, but lost the screws," Tina recalls with a laugh. "I couldn't find them and he couldn't tell me where they were. So I went over to Home Depot and they helped me. He took the screws out of the power box, playing with the electricity. When I'm not in the room with him he's in trouble."

During a support group meeting I attended through Midway, I encountered a woman who had similar issues with her husband. Similar to Tina's husband, he was always a handyman and was used to handling all household tasks on his own. Lately, due to his dementia symptoms, he no longer had the cognitive capability or body control to execute many of these tasks. Issues arose when he would still attempt to perform these duties, and his wife was concerned. She had arrived home ones day to find her husband at the top of a ten-foot ladder attempting to change light bulbs in their living room. Despite her efforts to hide the ladder, he always managed to find it. The woman was at a crossroads because she felt that they needed a ladder in the household in case of emergencies, but as long as it was around her husband was at risk for falling off of it. Another member of the support group voiced that they had encountered similar problems with her father, and the only way they remedied it was to leave the ladder at her brother's house and only bring it over when needed.

Due to situations like this, CGs must often to modify their homes. As Christy put it, "it was almost like baby proofing, but in reverse." In the CR's condition they may not realize that they are endangering their safety, or they may simply be trying to entertain themselves. However, CGs must anticipate these problems and plan accordingly. For instance, Lisa's brother installed a lock at the top of his doors instead of the bottom to prevent their mother from wandering outside at night. Russell constantly checks the locks in his home: "I've got to be real careful. Can't keep the doors open for a second, she's always trying to get out of the house."

Christy and her husband made significant adjustments to their home, especially in the bathroom, to accommodate her father's condition. Despite this, he still had safety scares:

> We've had to make a few changes, like we put grab bars in the bathroom and near the tub. Because the one time he did fall he somehow fell into the bathtub. I think he grabbed the shower curtain and swung around. He was sitting in the bathtub, he didn't hurt himself, he was just sitting there. I was like, 'What did you do?' But we also have a raised toilet seat, and my husband put some kind of post by the front door so when he's going up the steps he has something to grab on to.

She recalled her father's bathroom incident humorously given the harmlessness of it, but similar issues have the potential to he dangerous for individuals in his condition.

One final way that dementia can make interaction with the CR difficult is when they do not fully recognize the situation at hand. While individuals around them may be trying to help, the CR may resist or not cooperate based on their ability to understand the context. For instance, Jamie's father often misled medical professionals, perhaps not understanding that by not disclosing his conditions they could not effectively help him:

> My dad kind of…how can I put it? He lies to the doctors a bit. Says he's not having a problem. Do I get in the middle of there and say what's going on? He won't do the testing. I'm sitting there in the room wondering how I manage it without being disrespectful to him and disrespecting his privacy with his medical care.

Russell's mother did not understand the transition she was going through for months after he moved her from India. Having never lived in the United States before, and coupled with her condition, the new setting may have triggered unpleasant emotional responses such as anxiety and disorientation. She could not comprehend that Russell had brought her there in order to take care of her. Although now he chuckles as he recounts the story, in the moment it was difficult for him:

> The first six months were very rough. Also because she was still with it enough where she knew she wasn't home. She knew I'd brought her over here and she would pack her bags almost every day. She'd get out into the garage and put her bags in my car and say, 'Drop her at the train station, I'm going home. Or she'd say, 'Call me a taxi.' She wanted to go home. That drove me crazy, and it went on for months. It was really hard. She couldn't conceptualize that she was so many thousands of miles away. It was just like she knew that this wasn't her home, that was it. Now we're way past that, there are no more problems with that. Cognitively she has declined quite a bit.

Dealing with Siblings and Other Family Members

Although one individual is typically the primary CG, the administration of care is often includes or requires input from others. Due to the social disruption associated with care (e.g. altering paid work patterns, changing frequency of leisure activities, learning new tasks associated with dementia care, etc.), these interactions must be carefully negotiated to ensure harmony. Brody et al. (1989) presented three concepts for characterizing interactions among family members in caregiving units. Although the original classification was only applied to siblings providing care to their older parents, the ideas can also reflect interactions among other relationships:

- Nonfeasance – complaints about things that their siblings do not do, such as not visiting enough, not doing a fair share, and not showing interest

- Malfeasance – active negative behaviors such as giving advice on caregiving that they do not follow themselves, tendency to do less but to tell others what to do, and resent helping and say they feel burdened
- Uplift – moral and emotional support, such as being able to talk about their feelings and knowing their siblings will be there when needed.

The perception that a member of the caregiving unit is not contributing as they should is associated with higher distress and caregiving for the primary CG (Ashida et al. 2017). Throughout my interactions with CGs I found that in nearly every caregiving unit there was one person (or more) who was perceived to not be "pulling their weight." This individual is a freeloader, i.e. one who is "taking the benefits of social exchange without reciprocating" (Workman and Reader 2004). As long as this individual is sure that someone else will pull their weight for them, they can get by without doing their share of the caregiving labor.

Despite having a sibling within an hour's drive of her home, Brandi fulfilled almost all instrumental care duties for their father.

> I am 100% responsible for him because my sister decided…it's another dynamic that has been hard to accept. But I've noticed that after readings and hearing from the people that I also have in the support group, it's very common. To have just one member of the family doing all of the work, and the other people don't do anything because they don't want to.

Brandi noted that her sister had the means to assist in some ways, but chose to do otherwise.

> Not really because they can't. They say they can't, but they don't want to. So my sister is like that, it took…of gosh, years of trying to understand each other, and finally I'm over it. It's okay. I still think she should do something, but she doesn't want to do it. It's hard for her. It's not as hard for me, I think because of the differences in who we are.

Brandi acknowledges that it may be difficult for her sister to handle some caregiving tasks, but does not believe that it excuses the perceived nonfeasance has toward her father's care.

Early on Brandi's sister did indeed assist more, but this assistance waned over time. Excuses such as work, social events, and other family activities were cited. She was still helping out a couple of days a week until one event changed the trajectory of their care provision:

> My sister was coming up to help, and she would only do it on the weekends. That's all the time they had. And my husband's birthday is in December, so we always like to take a weekend trip, or 4 or 5 days off at our birthday. And she said to me a couple of years ago, maybe two Christmases ago, she said, "We're just not going to be able to come in December anymore. December is just too busy for us. So y'all can't go anywhere in December unless you find somebody." So that's when we decided, "Let's just pull completely away from relying on the kindness of my sister to come and do whatever she can around her social life and work life."

Her sister's nonfeasance had reached the point where Brandi felt that she should take control of all care-related responsibilities for their father.

Tina experienced similar nonfeasance with her brother, who lives in the same city that she does.

> My brother [who lives about an hour away] will give me a Friday night or a Saturday night off sometimes. The other brother who lives here who was supposed to have her every other weekend so we could get a break, about three months ago said he couldn't handle it anymore. So, okay. Whatever.

Despite living the closest to Tina out of all of the siblings, her brother (who was only providing care four days a month) could no longer handle the responsibility. Currently, Tina provides basically all care without the help of her siblings since they have mostly ceased their assistance.

In both Brandi and Tina's cases, they willfully decided to take over all care responsibilities after the care they were supposed to be receiving waned. While this assistance in care was meager to begin with, they decided to essentially eschew help altogether and take complete control themselves. This may also be due to their perceived superior caregiving capabilities in the eyes of their siblings. Section factors may be associated with caregiving. For instance, there is evidence that among married CGs, those with the strongest marriages are the most likely to take on multigenerational caregiving responsibilities (Loomis & Booth 1995). While it is possible that Brandi's and Tina's siblings dropped out of care because they didn't want the responsibility, it is also possible that all parties involved view Brandi and Tina as the most capable in the family at providing care anyway.

The CR may also perceive their care networks as having varying degrees of competence. Although Jamie has a sister who lives closer to their parents than she does, their mother and father tend to call Jamie more often when problems arise:

> For whatever reasons they seem to be more reliant on me than they are on my sister. I'm not sure why that is, if it's because I'm in healthcare. My sister is the older child. I don't know what it is, but it seems like the phone calls come to me, and if I can't manage it I call her and ask her to do it, because I just can't right now. But a lot of it falls on me.

It seemed that Jamie did not necessarily blame her sister for the inequality in care provision, but was still a bit irked that the disparity exists. However, even if one individual in a caregiving network provides more care than others, the relationships are not necessarily antagonistic. Friends, family, and other individuals, even those who actively choose not to provide more care than they do, may still play important roles in the primary CG's ability to operate. Though she provides more care between the siblings, Jamie's husband plays an important role even without actively providing care himself.

When asked if she has any strategies for making care more tolerable, Jamie had this to say, with a laugh:

> Griping to my husband. Poor man, bless his heart. I blow off steam with him, because that's safe. And he just says, "Rave on, baby." Both of his parents are deceased so he's been through all of this, so he says, "Yeah, I know. Tough to watch, tough to deal with. You're right."

Kimberly's husband fulfills a similar role; despite not providing the same degree of care as Kimberly does, he is integral in effective care provision:

> Looking at how much support I've gotten from my husband…it was interesting because in the last year, when we were starting to deal with the more aggressive antagonism, the frustration, there were times when my mom wouldn't talk to me but she would talk to my husband. Which surprised us all! But that was a huge support for me.

Kimberly stated that feeling insulated and supported by those in her family helped her continue on.

> When you talk about family dynamics, it's not just the first level. It's also the next level of family members who are supporting the person who is giving the care. So that was incredibly important, because even though my siblings weren't there for the majority of this time, when I would call I would just be able to vent. Knowing that I could do that…being able to get input. That was a level of support to help me keep going.

Russell's siblings and other family members provided almost no instrumental support for the care of his mother, yet he felt fulfilled simply by the recognition they give him: "It's been nice because of the appreciation I get from the rest of the family, brothers and sisters, aunts and uncles. They always say good things, and many of them come to visit. It's been great because otherwise no one ever would've come to visit me," he says halfway jokingly with a smile.

> But because she's been here anyone who is visiting from anywhere in the world, whether they're visiting New York or LA, they always make it a point to come here and spend time with her, so I've gotten to see a lot of my family ever since she came.

Support from Other Family Members

While having a friend of family member who is available when the CG needs to vent can be useful, secondary CGs (i.e. anyone besides the primary CG who also provides instrumental support) can bring even greater benefits. In a sample from Hong Kong, primary CGs experienced cognitive benefits in the presence of a supportive secondary CG; they have a lower probability of experiencing psychological distress as well as more positive mood symptoms (Lou et al. 2015).

April provided the care for her parent by herself through most of their caregiving needs, but recently her sister began picking up a bit of the slack.

> It all just worked out so well. My sister has been helping me for probably about a year now. Before she started helping me I literally did everything. I needed help. They'd help with some things like going to the doctors' appointments. When you have two people who both have to go to the doctor it's a lot of appointments.

Something as simple as helping with transportation to doctors' appointments can help April to avoid having to leave work or missing work days altogether. Her sister's assistance even allowed April to take a long-overdue vacation.

> I was so happy to get her in the system, because I wasn't taking any vacations. That was hard on me. For years I didn't take a vacation. Years, years. And last year was the first time, I took a week off and she stayed here with Momma. Because if I take her out of her element, like if I take her to my other sister's house, when she comes back here she's lost. I'll never do that anymore, I haven't done that in about two years now. She can't distinguish two different places, she really can't. It's hard for her.

Jermaine and Sherry's daughter was willing to relocate over 1,000 miles to assist her parents when their care needs arose.

> We are blessed with the fact that our daughter, who lived up north with her family, they moved down here about two years ago. They have the grandkids, the grandkids are upstairs right now. My daughter works and her husband works. We moved here because my son and his wife live about half a mile away. So there is family support, and we're blessed with that. We moved down from because my kids came up and took a long look at her and me, and decided the old man wasn't cutting it.

Jermaine finished the last comment as he grinned at his wife. Jermaine and Sherry even provide a bit of care for their adult children, as they are home to watch the grandkids when they are off from school. Now that the entire family is within close proximity to each other, life has been easier for them. Jermaine described everyone’s role in care provision: “Our daughter takes care of all of the medicines. I dispense it to her. My son is handling the financial aspect, that's something that he's more responsible for. He and his wife are pretty good at that.”

Jillian and Ken had perhaps the best caregiving system I encountered throughout all of my interviews. They organize their agendas to compliment each other’s time, provide for all their mother’s needs, and help each other in a selfless way. Both of them recognized how lucky they were that it worked out this way, as well as understanding that not all siblings manage such an effective system. As Jillian mentioned:

> My brother and I, I do have a sibling, thank God. Because I think if I had to do this myself I’d probably pull my hair out. We have our schedules, during the week and on the weekend. We plan our vacations to a tee. If I’m going out of town I get help, if he’s going out of town he gets me help. It works out.

Ken also realized that the system he established with his sister was beneficial for all parties involved:

> But yeah, I’ve shifted how I live, how I work. But my sister and I are good, we’re siblings that don’t fight. When we were younger we did fight on, but once we got

> into our teen years and stuff like that we realized that we only have ourselves to depend on. We don't need to get into the fighting and bickering thing, so we don't. On weekends we have a set pattern. She'll come to pick her up for a little bit and I go out and do my stuff. I'll come back and make sure she eats, and later if I need to go ahead and leave the house I can. We've got a constant text chain going on. If something really bad is going on we get a call. If it's a call we know to answer the call.

For Ken, providing optimal care for their mother is more important than any other family issues that may arise.

> I'm not going to say we don't have disagreements, but we don't have time for all of the other family drama that people like to engage in. We don't have time for that, we have to worry about her. That is a hurdle, hill, whatever, that I don't have to die on. That's somebody else's that they can do whatever they want to do. But we're just going to make sure that we get things taken care of.

However, even though some people have support available, they do not rely on these networks at all times. Some caregivers prefer to attempt handling care themselves if at all possible without interfering with anyone else's life. For instance, some of Tina's children live nearby, but when it comes to caregiving she only calls them in emergencies. She recounted the following narrative with a chuckle:

> Do I have support? My son has a three-year-old and an under-one-year-old. His wife is a pediatrician and he's in a startup engineering company, so he's working 80-hour weeks. He's on year four. Is it going to make it? I couldn't even tell you. It has something to do with the cloud, that's all I know. He tries not to travel, but on a day like today, both of the boys are sick. So he's sick because they bring everything home from the day care. His wife just started the new clinic job this week, so I know she's not taking off. So do I call him? Not unless it's bad.

HOW DOES CAREGIVING AFFECT OTHER ASPECTS OF LIFE?

Caregiving responsibilities often interfere with other aspects of the CG's life. Although some roles cannot be altered or abandoned, CGs may make concessions in other aspects of their lives to accommodate care. For instance, while older age is associated with fewer physical activities in exchange for more passive ones, caregiving can compound this factor (Queen et al. 2017). Time restrictions can explain some of this pattern, and increasing caregiving demands are associated with increases in both activity restrictions and depressive symptoms (Nieboer et al. 1998; Smith et al. 2011). This shift toward inactivity can be an important indicator of health preservation and management of stress.

Perhaps the most widely-discussed among respondents, one major way caregiving influences other aspects of a CG's life is the reorganization, reduction or elimination of social activities and events. Many reported that their time spent with friend or other similar activities were among the first to go when their schedules became packed due to care provision. Lisa used to have get-togethers with friends regularly; her mother cannot stay home alone, so now Lisa and her husband either have to hire someone to stay with her or just not attend: "It's gotten to the point where if [our friends and I] want to see each other, they pretty much have to come over here. My mother would not be comfortable going over there. She would shut down in a heartbeat, because she doesn't remember them. If they were here she can pretend she remembers. But she's in a familiar setting so it doesn't make her uncomfortable. But if we're over there it makes her feel so uncomfortable, so we just don't go around."

Early Stage Caregiving	Middle/Late-Stage Caregiving
Asking for and accepting help from doctors and other sources of support	Coping with major changes in behavior
Discovering how to maintain meaningful interactions with the CR	Dealing with major communication issues
Finding activities that are meaningful to both the CG and CR	Feeding, bathing, and other activities of daily life
Keeping track of medications	Keeping the CR mentally and physically stimulated
Learning to stay healthy and socially engaged as a caregiver	Learning to lift the CR
Managing anxiety about what to expect as the disease progresses	Managing the CR's pain
Managing other emotions such as denial, fear, anger, and/or depression	Protecting against influenza and pneumonia
Providing some transportation for the CR	Providing all transportation for the CR
Taking a larger role in instrumental activities of daily living (groceries, cooking, etc.)	Treating cuts and scrapes

Table 7: Common Adjustments Associated with the Caregiving Role [Source: Alzheimer's Association (2017)]

Jillian has similar issues with her mother. Although she still makes an effort to see friends and family, the time she spends at social events has been drastically reduced. "We'll go, but we'll only go for a couple of hours. And then you feel bad because you're really starting to enjoy yourself, but you can tell she's getting agitated." Others who understand her situation often attempt to accommodate Jillian's mother, but it is not a simple task to do so.

> Okay, so then they say, "If you're so nervous we'll turn down the music, do this and that." But they just don't understand, it's time to go home. Time to do the routine. Get her changed, get her hair done, put her to bed. It's just like a kid. Just like when you have children, they want to be home you better take them home dammit!

She finished her remarks with a hearty laugh. “There’s no talking about it.”

While many social events have been constrained due to caregiving, Jillian believes impromptu events have suffered the most. She states that she cannot attend any event without extensive planning beforehand:

> We can’t, because now I have to worry. Does my brother have something to do? Is Mom going to be okay? No, we can’t go because I’m worried that she might leave the house. It’s those spur of the moment things, I just feel trapped. So it’s those things, being able to, when someone calls and says, “Hey, do you want to go to a movie?” and I have to say I can’t because I’ve got my mom. Things like that that I really miss a lot. If I got that time back I don’t even know what I’d do with myself. But for us that’s the biggest deal.

Tina, a churchgoer her entire life, no longer attends. Although her husband is not liable to speak out at inopportune times, he has a very active disposition. Tina reflected on how his behavior has affected her religious life: “We no longer go to church because I can’t handle him in church. He doesn’t really act up but he gets restless. When he gets restless he’s got to get up and move.” Religious services and participation are a strong source of social cohesion and support, and losing the ability to participate may have contributed to Tina’s reduced social network; since she and her husband relocated she has not established a solid group of friends. “I have been slowly trying to make friends my age. It’s going to take a while, and it may not ever happen.”

Avocations and hobbies are also affected. Jamie, who enjoys dabbing in various personal and self-fulfillment activities, has all but given up on seeking those opportunities:

> I’ve kind of given up trying to sign up for things. This eldercare group was kind of an eye-opening experience of the demands of time for taking care of them, just a thousand and one things that can come up that they need attention for. I signed up for a meditation group to try to calm my brain down a bit. Hopefully that will

> work out, but it might not. Hopefully it will. If it doesn't, it will be another life lesson. To not do stuff like that.

She cited the unpredictable nature of her parents' conditions as the main culprit for the reduction in activities she experienced.

> There are things I kind of mourn being able to do that I enjoyed, in terms of signing up for stuff or being available to do things. I like to train dogs. It's kind of hard to take a class when you don't know if you're going to be there or not.

Despite her feeling of responsibility to her parents, Jamie finds it difficult to ignore the impact it has had on her ability to do things she enjoys.

> I try to remind myself that the bad news is my parents need a lot of care. The good news is that I still have my parents. They're still around, and there are things I enjoy about them. They're still my parents. They're these people that I care about.

Caregiving also restricts the frequency of travel for CGs. Kimberly, whose husband often travels for business, used to take her along for some of his business trips. However, once she became the primary CG to her parents this trend slowed considerably. "It definitely impacts the whole family," Kimberly stated. "You can't travel, you can't go out of town. Because you've go to have backups." On the occasion that she did travel, Kimberly set up an extensive network of family and friends to manage the care of her parents until she returned.

Katharine is also a well-traveled woman, and used to go on trips with her mother until her dementia became a problem. Katharine recalled their relationship:

> She was a professional woman… We used to travel together all the time or go to the symphony, the theater, go out to eat. We used to do a lot of things together. Last summer I did get her to some orchestra concerts that she was able to sit through without complaining too much, and that was the last time we went out together anywhere, last summer.

Adjustments to Marriage and Family

As an adult child CG, the caregiving process can have adverse effects on marriage. On average, “experienced caregivers report less marital happiness, more marital role inequity, and greater hostility than recent adult child caregivers,” suggesting that the negative effects of caregiving on spousal relationships accumulate over time (Bookwala 2009). Respondents also spoke about how the time crunch associated with caregiving can impact their children. Jillian, who is a mother of two young kids, recognizes that her kids do not have the same freedom that they would if she did not have to provide care: “I see it mainly with my family because they’re like…they’ve got the routine down now, but before when we were really trying to start out and figure out what we’re doing, they’d always be like, ‘Do we have grandma today?’” Jillian imitated her kids in a whiny, nasally voice.

> And I have to say, “Yeah, I’m sorry.” I feel so bad that they feel like I’m trapping them too. It should just be me. I would say that’s probably the biggest thing. And if my brother was here I think he’d tell you the same thing. Planning family vacations gets hard because if you thought planning around kids’ school schedules was hard, now I’ve got a third kid.

According to the intergenerational stake hypothesis, middle-aged adults may be more invested in the wellbeing and development of their own grown children than they are in their parents (Kim et al. 2017). This does not necessarily indicate that these adults care more about their kids, but they may see the task of developing their children’s skills and personalities as more apparent tasks. This may help explain why being an adult CG for parents may be stressful, since this task takes away from other more salient responsibilities.

Adjustments in Public Settings

Multiple CGs referred to the public nature of dementia as a major adjustment they had to make. The actual provision of care is mostly private, but on the occasions that they took the CR to a public place they had to manage their condition for all other people involved. There was a common sentiment that most people in society do not know how to interact with IWDs, so the CG had to mediate. For instance, Roberto spoke about a time when he took his wife out to dinner with family:

> The other thing about dementia is that by its very nature it causes you to be isolated. My sister and brother in law were visiting when my wife was living at home, and we went out to have dinner. We’re sitting there, and one thing you learn is that you can't give people with dementia options. I would just say, whenever we'd go out to dinner, I know she can't make up her mind. So I'd say, “You know, you like the catfish. Why don't you order that?” So we're out at dinner and the waiter had just served us the meal, and she said, “Box it up.”

Roberto then imitated the waiter’s facial expression after the strange request. He held his mouth agape with a shocked expression for a while before continuing.

> You learn to say, “We're dealing with dementia.” And one of the things that a lot of people don't tend to want to do is tell everyone around them what is going on. There are some people who want to just keep it hidden.

As he says this, Roberto holds both hands, crossed, close to his chest, as if clutching something.

> And you can't do that because everyone they interact with recognizes that there's a problem. If they understand what the problem is, then they can be supportive or not do something to make it worse.

Jillian encountered similar problems when she took her mother shopping:

> That’s another thing, when you take them to places I’ve found myself having to explain right away. “She has Alzheimer’s, so if you’re going to ask a question you

> need to ask me the question. Please don't direct the question to her." Because she might say something strange and then they'll be confused. You worry. Even taking her shopping for shoes. God bless those people, it's their job to come up and ask if they can help, and I say, "No, I think I've got it."

Despite this interaction, Jillian often had to eventually go into more detail with store employees.

> After being bugged about twice I'll say, "Look, my mom's sick, just let me do this. You're going to confuse her and she'll shut down on me, and I won't be able to buy her shoes. She needs these shoes. So just back up from me, let me handle it. I promise I'll buy something." But by that time, once you point it out all they do is stare. We're not some freak show. So then now your whole shopping experience turned into a nightmare, you're just like, 'Get a shoe on and let's go!' it's just things like that you have to adjust to.

Adjustments to Employment

Finally, most of the employed CGs in the sample had to make some sort of workplace accommodation to provide adequate care. April, who had two jobs, was forced to quit one when the time constraints of caregiving became too restrictive.

> It changed [my life] a lot, because I was used to being by myself. I was working two jobs matter of fact. I let one of the jobs go once they came to stay with me. I was just so used to getting up and going. I like to go, you know? It slowed me down. That was just a part time job. The job I have now, I've been there 33 years. That was just a little extra job. You know how you get caught up with credit cards and things. I had a few bills.

She finished the narrative with a lighthearted smile. Although she didn't need her part time job to survive, it kept her ahead on all of her bill payments, which she had to sacrifice.

Jamie, who teaches classes, had to completely reconfigure the way she graded papers to guarantee that she would have enough time to fulfill all of her obligations:

> I'm trying to sit in a hospital room and prepare a course, or sending emails to students and getting courses arranged while my mother is complaining on something and people are coming in and out. While I'm trying to concentrate on grading student submissions, trying to give it the attention it deserves. I'm trying to work here. It's extremely stressful.

She admits that the quality of her student feedback suffered once her parents became ill.

> I wind up feeling like I'm not doing any of it as well as I have historically. I certainly feel like if students put effort into something and try to do well and demonstrate that they have attained a level of competency with something, I have the obligation to at least make the effort to make responses on it to match the effort that they put into it. And trying to do that from a hospital room where doctors are coming in and talking to me because Mom can't hear them, or asking me if I'll sign for something because Dad's a bit out of it right now. It makes that whole process difficult.

Roberto was able to juggle caregiving and work quite well, and luckily he did not have to make significant adjustments to his routine or schedule until his wife had declined significantly. However, his company was accommodating and allowed him to miss work when necessary.

> Only at the end [did I have to make large adjustments to accommodate caregiving]. I was working in real estate and it finally got to the point where I was spending a lot more time with her, so I just had to tell the people at work the reasons they didn't see me around much. The owner of the company's parents both had Alzheimer's, so he was very accommodating.

Finally, Russell may have had the most malleable schedule of all employed CGs in the sample, mostly because he is the owner of his business. This autonomy allows him to mold his workday around caregiving in a way that most others cannot:

> Luckily I own my own business. If I didn't, I couldn't be doing all of this. My office is half a mile from here, right around the corner. I'm often home twice a day, I can come home and have lunch with her. I can work any hours I want since

> I own the company, so I take great advantage of that. So I'm home until 10:00 two days a week sometimes. I leave at 5:00 on the dot, and I schedule my meetings around what needs to happen. Pretty much every day I'm out of there before 5:00, either because I come home or because I have to pick her up from Summit. So that has definitely cramped my time at work, but I can get quite a bit done at home, so it's fine. It's not that big of a deal.

Transportation

Even in old age driving tends to remain the preferred method of transportation, and older adults often resist driving cessation for as long as possible. On average, older adults "outlive their driving days by 11 years for women and 6 years for men (Foley et al. 2002). Many elderly drivers slowly transform their driving habits to avoid challenging situations, such as being on the road at peak traffic times or at night, to compensate for age-related declines and possibly prolong driving (Dickerson et al. 2017). Although driving may curtailed for IWDs as a safety precaution, taking away their ability to drive also creates greater transportation pressures on those caring for them; this is "especially true in suburban and rural areas, where most older adults live in North America" (Rosenbloom 2012).

Numerous CGs noted that when dementia or old age took away the CR's ability to drive, they felt more pressure and responsibility to pick up the slack Jamie had to transport both parents when her father, the primary driver, could no longer do so:

> Actually, there were a couple of times when…I can't remember exactly what the situation was, but I wound up driving over to take them to doctors' appointments. There was some reason he couldn't drive, the doctor had told him he couldn't drive. I may have been when he broke his hip the second time. The doctor told him he couldn't drive until he was released from care after the broken hip. They were able to putter around in their house, but he was not able to drive. So I drove over to take them to doctors' appointments and go to the grocery store for them.

Jamie’s parents lived over an hour away at the time, and carving time out of her schedule to take them everywhere proved to be a significant task.

Randy and Susan were in a similar situation. When his father was alive he did most of the driving, but once he lost this ability either Randy or Susan had to transport them. Randy recalls, “We started there, but we were going back and forth for at least a year before we moved her up here.” Susan remarks that they were traveling over an hour to meet them at least once a week at that point. “Before that it was about every two weeks, and from there it progressed,” Randy continues.

> It was a lot harder doing that every weekend, having to drive down there. Even during the week for doctor's appointments. It's definitely hard. Sometimes we'd get home and his dad would call because something had happened, and we'd literally have to turn right around and go back to take care of whatever it was.

At times, the CR takes a stand against driving cessation and refuses to give up their keys. Driving is often one of the last true sources of independence elderly adults have, and losing this ability has both practical and symbolic consequences. Kimberly’s father challenged not just his family, but also the doctors when told that he should stop driving:

> My dad was one of those who…he was very headstrong. Determined. After he had his stroke and when he was in the rehab hospital, we were talking with him and with the doctors about how he needed to quit driving. The macular degeneration was really bad, his reflexes were slowing.

Although he was going through clear physical changes, he was still clearheaded and unwavering.

> Cognitively he was still there, but the physical effects were problematic. And he would sit there and argue with us. And argue with the doctors. He would say, “God will tell me when it’s time to stop driving, and he hasn’t told me that yet.”

> Mom was more passive, but Dad was more “Come hell or high water I’m doing it my way.”

Jamie’s father was similar. Despite a long list of ailments he continued his attempts to renew his license, and was eventually successful (to Jamie’s astonishment): “Dad just got his driver’s license renewed last week. Apparently being 95, in a wheelchair, and on continuous oxygen are not exclusions for a driver’s license. I didn’t know that.” She chuckles as she continues, clearly flummoxed.

> I said, “He has medical conditions, he shouldn’t have a driver’s license.” So the lady asked what those conditions were. She said a wheelchair is not an exclusion. Continuous oxygen is not an exclusion either. I said, “He’s 95!” She said, “Well…actually age is not an exclusion either.” And they gave him the driver’s license. Fine with me. I don’t think he can get to the car, but they gave him a driver’s license.

AMBIVALENT AND UNEXPECTED EMOTIONS IN CAREGIVING

Caring for a family member is an inherently emotional process. For those who are extremely close to the CR, it can be painful to witness them in a physically and cognitively deteriorated condition; it can also be painful to observe how the CR’s condition affects the rest of the family members outside of the caregiving dyad. Even if the CG and CR did not have a great relationship prior to care provision, the CG may feel somber as they observe the gradual decline in health. On the other hand, some CGs may find joy in the ability to provide a much needed service to someone they care about. In the absence of a strong emotional connection, some people, such as paid CGs or other care workers, may simply take pride in their jobs or the fact that they are making someone’s life easier. However, many family CGs experience emotions that they do not anticipate, and may even be afraid or ashamed of the sentiments that occur. *Psychological ambivalence* refers to “the contradiction of simultaneously holding positive and negative sentiments or emotions about family relationships" (Connidis 2015). For instance, ambivalent CGs may concurrently detest the caregiving process but love the resulting comfort that it brings to the CR. This does not necessarily imply that there is an "equal level" of positive and negative emotion; the CG may feel mostly angry that they have been put in the position to provide care, yet have lesser feelings of joy since they ease the pain that the CR perceives. However, there is still a tension between seemingly incompatible sentiments.

Ambivalence creates opportunities for feelings of burden due to its seemingly paradoxical nature (Connidis 2015). For instance, an individual may feel intense confusion if they waver between joy and resentment during the caregiving process. Even if a CG is mostly pleasant while providing care, they may become angry with themselves when they encounter moments of stubbornness; they may not always *like* the things they feel, which can potentially lead to psychological distress.

Additionally, there are *feeling rules* associated with caregiving; feeling rules are "social conventions regarding accepted feelings" (Simpson & Acton 2013). For example, among middle class white people, it may be a common social convention that one should be sad at funerals, but not overly sad. Being too joyous at a funeral, or being at the other end of the spectrum and wailing loudly and uncontrollably, may be looked down upon. Based on social norms and values, there is a "proper" way to behave despite funerals being intensely emotional and often tragic events. CGs may sometimes violate feeling rules by experiencing emotions that they believe fall outside of the socially accepted range.

For instance, although April loved her father dearly, his approach to being a CR did not make the caregiving process any easier. He consistently attempted to override April's decisions and often failed to show her respect as an adult. While she wanted to care for him and make his final years as comfortable as possible, she hated the way some of their interactions made her feel:

> There were times he had me in tears, seriously. I thought I was going to go ballistic. There were times where I thought I was going to have to say, “Look, y’all need to go. Move out.” I really felt that way, more than once. But like I said, the Lord works in mysterious ways. He helped me to hang in there with that situation. And I’m glad I did, I’ll be damned. I don’t know if anybody else, among my siblings, would’ve taken care of them like that. I’m not saying they wouldn’t have, but I think God wanted them with me.

April looked religion for strategies to move through those difficult times. When her father eventually passed away, April’s caregiving career became much easier since she only had to care for her mother, with whom she shared a more harmonious relationship.

Jamie had a similar outlook on the caregiving process. While she wanted the best possible care for her parents, the daily tumult associated with delivering it aggravated her with the way it interfered with every other aspect of her life:

> I really don’t mind taking care of them, but at the same time there’s a sense of irritation with things that I’m not able to do. I’d like to take a dog class with my dog, but I’m afraid to sign up for anything because I know there are going to be doctor’s appointments. Or there will be some other kind of emergency. Oh, my mother couldn’t urinate and she wound up in the urgent care center. And after there, she wound up in the emergency room. It started at 7 o’clock in the evening and didn’t end until after midnight. Things that are kind of out of the blue like that. You can’t really plan for them, they’re just there. So there’s a sort of angst about always being on call, and never knowing…when the phone rings, is it because you just want to know why the paper isn’t there today? Or is it that EMS has been called? And realizing that it’s not going to get better, things are only going to escalate from here.

Jillian had a similar outlook; she is ecstatic that she and her brother have a symbiotic relationship and are able to provide adequate care for their mother without having to institutionalize her, but she also has a constant feeling of dread in the back of her mind:

> Thankfully we've been good, but it's one of those things. When I drive away today, is today the day? The day my brother comes home and says, "Where's Mom?" It's not like we can put a GPS on her. I wish we could put a whole tracker in her. And I wouldn't even know were to look, I'd have no clue. The good thing is that she was born and raised here, so we have two ideas of where to go. But is she going to know to go there? We wouldn't even know where to start. And don't even get me started on the police, because you've got to have the whole "missing for 24 hours" thing. I think when you start to worry about things like that, it's when you have to start looking for nursing home facilities. So I don't have to cringe every five minutes.

CGs may also be ashamed of the feelings they have about caregiving or the CR. The constant nature of providing dementia care can drive a person to feel things they never anticipated. For instance, despite having a happy marriage for decades, Tina admitted that she is simply tired of caring for her husband. This is clearly not an endearing emotion to recognize, but she has come to terms with it: "I've been going through this for 12 years. It's too long to be a caretaker. I'm tired. I'm not ugly to him, but I certainly can't have the same feelings. I'm so tired of taking care of him. I'm tired." Given the opportunity, she would institutionalize him without hesitation.

> I'm ready to put him in if something were to happen. And I can tell you, if I won the lottery, which I don't play the lottery, but if I won it, I would put him in tomorrow. And I would see him periodically, but it would make absolutely no difference.

As much as Jamie cares for her parents' wellbeing, she would loathe having to take them into her own home. Jamie is not willing to take on the emotional burden and make the necessary lifestyle changes to accommodate them:

> I cannot imagine them moving in with me. I just…I just can't. Mother can easily burn the house down. Even when they were at home she was putting stuff on the stove and forgetting about it, and not realizing it until the house filled up with smoke. And I'm afraid she would try to help, and the next thing you know the fire department is out there. In addition, I have a lot of pets at my house and it's just not really build for that, we're not set up for mobility-impaired people.

However, the other candidate for supplying care is Jamie's sister, and it would be a difficult transition for her as well.

> My sister's house is two stories with bedrooms upstairs, and there's on way they can negotiate stairs. They just can't. So I don't know if them moving in with us is feasible for either one of us without us just giving up our lives completely. And that is concerning to me if it gets to that point.

Katharine reached a difficult point in her relationship with her mother because of other people involved in the care network. Katharine handles all of her mother's affairs, such as finances, but the day-to-day personal care is administered by a series of live-in caregivers; Katharine and her mother live separately. As her mother's condition worsened, Katharine noticed that she was beginning to feel a stronger connection with one of her live-in caregivers than she had with her own daughter. "Well yeah, she thinks of [the main live-in caregiver] as the daughter she never had," Katharine says with a laugh.

> Seriously. That's another thing...people have a tendency to bond really strongly with their caregivers. It used to really bother me, but I don't care anymore. Her social life is her caregivers. She lives in a condo, so sometimes the neighbors will come by and say hello. Like I said, they used to have bridge a lot. Now they don't have that much anymore. I go when I can, but I'm there and she can't talk. I can't have a conversation with her. So I don't stay very long, I don't go very often. But I go when I can.

Katharine's relationship with her mother has changed drastically, and at first she was bothered by her mother's closeness to the live-in caregiver. But over time Katharine was able to move past these uncomfortable emotions and reach a stage of peace.

PERCEPTIONS OF ADULT DAY CENTERS

For the Care Recipient

Throughout my research, each individual who utilized ADC services had a positive opinion. Some reviews were more glowing than others, but I did not encounter one negative statement about Summit or any other ADC. There may be selection bias here, as anyone who is dissatisfied with the service may leave the system quickly, reducing my chance of coming into contact with him or her. Additionally, those whose opinions may be at odds with the operation of Summit or the way they deliver care may never go to them in the first place. Even among respondents who had never used ADC services, none of them had a negative opinion of them of the care they provide. This is in contrast to some other systems of care that respondents did have strong opinions of; I spoke to multiple individuals with less-than-stellar opinions of assisted living facilities, nursing homes, and/or primary care professionals.

Senior centers, ADC, and other similar institutions "can foster meaningful personal relationships (connection), enhance self-efficacy (control), engage participants in leadership and peer support roles (contribution), and offer new educational opportunities (challenge) (Aday et al. 2006). ADC services also make many of these benefits available to populations that may not have access to them otherwise. Most CGs recognized the benefits of cognitive stimulation that Summit provides.

Russell noticed a difference in his mother between the days she attends Summit and days she does not. "Right now I know that the two days that she's home she's pretty bored out of her mind. Walking around, fidgeting, picking up things and getting in trouble all the time. She'd be happier at Summit, but I don't want to lose my two day-a-week caregiver, which it why I'm still doing it. But at some point I probably will.” I asked what it would take for him to consider using a more institutionalized form of care, and after a bit of deliberation he replied:

> If you're asking what the threshold for putting her in a home? I don't know. I think I'll know when it's time. It's not out of the question. It's definitely not time right now because she knows me, she knows my kids. She interacts with us and enjoys the affection and love. As long as that's there, there's no reason to put her in a home.

Jermaine also noted the benefit of having a more active environment than the one Sherry would experience at home.

> I think she's engaged. Obviously I'm not there to watch her, but I hear every once in a while that she participates. And even if she doesn't participate there's clearly activity going on around her. For her, stimulation has to come from the outside. She can't do it for herself. I think it's good for her to go there. That's a really nice place, very unique place.

Tina was the only person I encountered who had a neutral opinion of one of the aspects of Summit. She did not dislike it, but she noticed something that she thought could use improvement: she felt that the activities at Summit were geared more toward women than men. Indeed, women greatly outnumber men among the members, but Tina felt as though the games, puzzles, and crafts that Summit tends to engage members with were not geared toward a masculine demographic. Beyond this, she was very satisfied.

> He’s very happy over there at Summit. And I know it’s important for him to go regularly and have a routine. We go at the same time every day and I pick him up at the same time. He knows that, even if he can’t figure out anything else, if I say I’ll be there then I’ll be there.

Although Christy had never used an ADC herself, she had a high opinion of them and the way they administer care. However, she felt that with her father's condition he would not benefit from the stimulation they offer. "It just seems like he sleeps so much that he wouldn't even benefit from all of the wonderful social activities that they offer, because he doesn't want to do anything." She, her father, and I were all sitting together during the interview, and she smiled at him as she continued.

> They could drag him out maybe. But I know he wasn't doing a lot where he was living before, other than playing dominoes. He used to be a really active younger person. He used to exercise and bike. Travel, he used to travel a lot. But not anymore.

Beyond activities, CGs found value in the bonds that their loved ones could form with others at Summit. Elderly adults who are integrated into networks that are rich in both variation and non-kin contacts have a higher chance of survival than older adults who do not have membership in these types of networks (Ellwardt et al. 2016). Non-kin networks include friends, acquaintances, neighbors, coworkers, etc.

Lisa was not expecting her mother to make many friends when she began going to Summit, especially since she resisted enrolling for a while. Eventually Lisa convinced her to go, and she began to enjoy it after an initial adjustment period. When I asked whether her mother still gets a lot out of the social environment at Summit, Lisa replied:

> I think she does. Something that surprised me, and still surprises me, is that she makes connections with some of those ladies there, and she remembers their names. She can't even remember my brothers' names sometimes. Then there's a couple of other ones that she immediately recognizes and connects with instantly, and I see a lot happier person when she gets to go and do that.

These types of connections can be especially important for older adults. Research by Suanet & Antonucci (2016) highlighted cohort differences in emotional and instrumental support. Due to social and demographic changes in the last few decades, individuals in later birth cohorts have greater access to and receive more support from friend-focused networks. Friend-focused networks are essential sources of various types of support. ADCs and similar services can provide friend-like networks to individuals who would not have access to them otherwise. Randy, speaking about his mother and the way she made friends at Summit, agreed. “I think being with their peers makes a huge difference too. They're comfortable with that. When they talk they have common things to talk about. They can relate to each other.”

For the Caregiver

Additionally, each CG who utilized ADCs appreciated the freedom they enjoy because the service: information, easier work schedules, or simply time to relax. Jillian values the resources Midway provides through Summit, as well as the way the environment engages her mother on a daily basis. When I inquired about specific things she enjoys, she replied:

> Oh my gosh, where do I start? They have helped a lot with information. The staff just sends all kinds of information through email. The classes the seminars, the books, people who will offer help. People at the office will mention, “Hey call these people if you’re trying to find a facility. Call this person.” She was the one who pointed us to an eldercare lawyer. Just a wealth of information. It’s godsend for both my brother and I since we work, it’s a perfect place to have Mom because she’s safe. On top of that, person-to-person interaction. I would hate to think of her being at home, just sitting there. I can only imagine what her little mind would do. I’m pretty sure it would go completely wild.

Ken also appreciated the way his mother was engaged, but importantly reiterated the idea that while she is at Summit, he and his sister do not have to worry about her wellbeing.

> With Summit I can go to work, I can be productive, I can get my stuff done from home, take care of her for the evening. We've gotten the schedule down pretty well. And it's piece of mind during the day. I don't have to worry. 'How's Mom doing? Is she eating? Is she being engaged?' She is being engaged because they also take pictures and videos of them doing stuff. I've seen my mom dance, I've seen her making stuff. Indeed, throughout my time volunteering there I noticed countless instances of staff members taking pictures of the members during activities so they could share with the members' families.

Christy recalled that even though her father doesn't use Midway, they have a program that gives CGs access to equipment that will help them in their caregiving careers. "So the senior centers are good, and then I've gone to programs offered by Midway. They have equipment-lending programs. We have a wheelchair that we borrowed from them."

Finally, April speculated on the prevalence of ADCs and the important role she believes they can play in the future.

> They need to have this in every city. Seriously, because where else are the elderly going to go? The nursing homes are filled up, and everyone doesn't want to put their loved ones in nursing homes unless they have no choice. Sometimes it comes down to that, but if you can put them somewhere else where they can enjoy themselves, it's the best thing they can do for the elderly.

CONCLUSIONS: FAMILY DYNAMICS OF CARE

Becoming a CG can involve structural adjustments such as altered work hours, rearrangement of household formations, reallocation of household income, and new methods of transportation. However, the interpersonal changes that take place can be just as jarring. Due to the nature of dementia care, those who interact with them must learn to accommodate a new personality and set of needs. This not only influences the relationship between the CG and the CR, but also the CG and any others who are a part of the household, extended family, or further social network.

While the progression of the caregiver career can strain some relationships, other relationships can evolve and strengthen. Individual CGs may attempt to handle care responsibilities alone, and some do, but interview respondents were quick to note how much they appreciate the assistance that they receive. Even if given in small amounts, social support can help stabilize interpersonal relationships when the caregiving career begins.

Chapter 4: Pathways into Adult Day Centers

LISA'S STORY

Lisa is retired, and her mother lives in a downstairs bedroom of the family home. Although he lives with them, Lisa's husband still works away from the household, her children are adults who have since started their own families, and her father passed away a few years ago. Given these circumstances, she and her mother spend a lot of time together at home. After discovering Summit, Lisa and her family felt like it would be a good place to try out.

Lisa's mother enjoys going to Summit now, but it was not always so easy to get her there. It took a lot of discussion and required difficult negotiations, but ultimately her mother warmed up to the idea of an ADC and eventually came to love it.

> The first four months, we'd get to that front door and she'd drag her feet, like, "Do I have to do in?" And now she get there and she's like, "Oh! This is where I'm going today. Great, I love these ladies." She enjoys it.

Her mother has even made a few friends along the way, which is especially encouraging since she spends most of her time at home isolated in her room. Lisa's mom prefers it that way. But over time, something about Summit brought out her social side. "The first four months I would walk in to pick her up in the evenings, and she'd be at the table by herself, watching everyone else interact. Now she is actually doing the stuff, playing the games, talking, or in circle time so to speak, like you do with kids," she recalls with a laugh. "She really gets into it and really enjoys being around these ladies."

When I asked Lisa if she ever considered an alternative to Summit, she was adamant.

> It's one of those things where I don't want to ever take her away from this if we can avoid doing that. Not take her away from that environment. She gets so much

> out of it. While she can still manage it, she'll go there. It's a nice break for me, but it's more for her. Because I'd figure a way out around things and have somebody come into the house maybe. But for her, it's a better place.

Throughout my fieldwork, I heard this sentiment repeatedly as I talked to CGs who utilize ADCs. For many of them it was a source of relief from caregiving in many ways; it either allowed them to work, gave them a break from 24 hour care, provided a richer environment for the CR than they'd have at home, presented a source of social interaction, or all of the above. But as discussed in Chapter 1, only a small number of IWD use ADC services.

In this chapter, I will analyze the pathways into ADCs based on my sample of caregivers, framing this process using the Three-Stage Theory (Esandi et al. 2017). Next, I will explore who utilizes these services, how they pay, and both macro- and micro-level factors influencing ADC use. Finally, I will examine patterns of help-seeking and the factors that guide which institutional interventions CGs choose.

THREE-STAGE THEORY OF THE SUBJECTIVE EXPERIENCE OF FAMILIES LIVING WITH EARLY STAGE ALZHEIMER'S DISEASE

When a family unit is faced with the prospect of providing care, what follows may be a whirlwind of events that they may or may not have been prepared for. The responsibilities associated with care are almost always considered stressors; even if they do not influence the CG's life in cataclysmic ways, there are adjustments that must be accommodated on behalf of the individual or family unit providing care. As covered in chapter 1, having a CR who suffers from dementia symptoms presents a unique challenge for many CGs, making the caregiving career more complicated than if the CR had no cognitive disabilities.

Esandi et al. (2017) created a framework for conceptualizing the process of adjusting to being a dementia caregiver for family units, called the *three-stage theory of subjective experience of families living with early stage Alzheimer's disease* (from here on referred to as the 'Three-Stage Model'). This model captures how families attempt to maintain balance in their lives when confronted with the prospect of caregiving and its associated obligations. It provides a general framework for the process that most CG units find themselves in, although it is not necessarily applicable to all caregiving situations, depending on individual circumstances. Additionally, caregiving units may oscillate between stages given the condition of the CR. As referenced in the discussion of Vaughn in chapter 1, the caregiving career is heavily dependent on the circumstance of the CR, and when their situation fluctuates the CG may be forced to reevaluate and adjust their own methods. Figure 2 provides a visual representation of the Three-Stage Model.

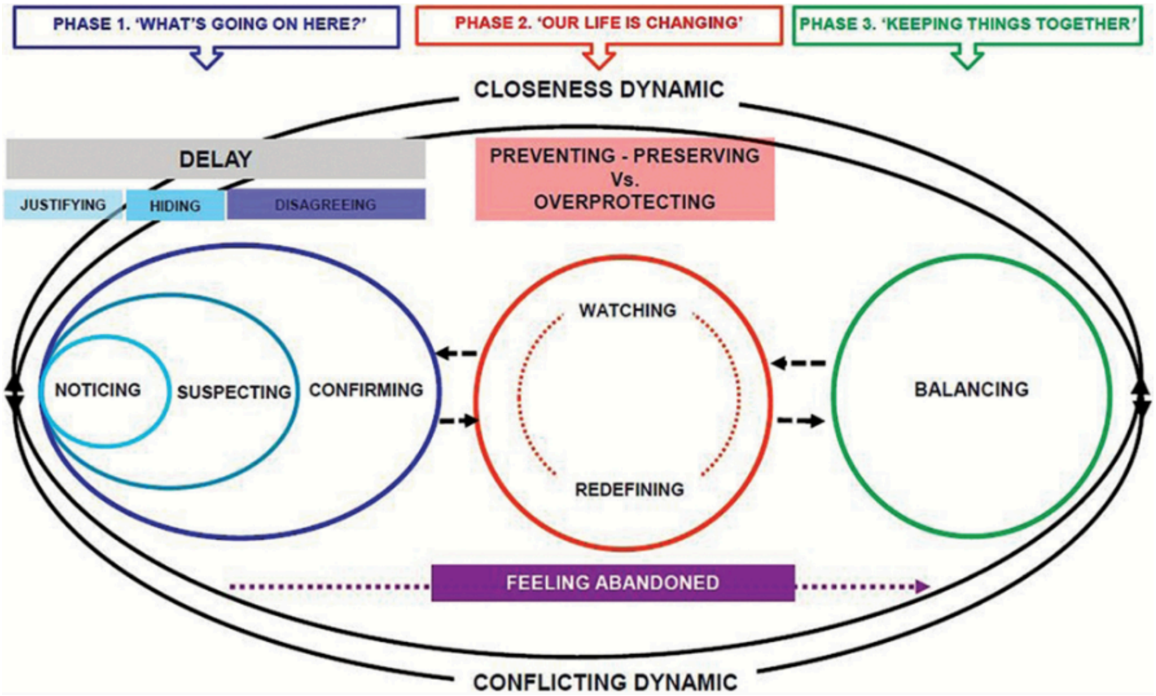

Figure 2: A Three-Stage Theory of the Subjective Experience of Families Living With Early Stage Alzheimer's Disease [Source: Esandi et al. (2017)

Stage 1

Stage 1 of the Three-Stage Model is referred to as *what's going on here*. It "comprises the social process of noticing, suspecting, and confirming and captures the families' growing awareness that something was not quite right with the person with (potential) Alzheimer's disease." This process was recounted by respondents often; many times, families noticed that small aspects of the (future) CR were changing, but not to the degree where intervention was needed. People close to the CR may attempt to justify these behaviors or ignore them completely. As time progresses and these small incidents become more prominent or consistent. The frequency of these episodes may be too consistent to brush off as a coincidence, and the CG may consult other family members and discover that erratic behavior is much more widespread than the CR is indicating.

Even from a distance, family members may notice that an issue is arising with their family members. Jamie lived about an hour away from her parents but would speak to them on the phone frequently, and despite not seeing them in person she picked up on cues. During a phone conversation she pressed her father about their dinner routine, and what he revealed was shocking.

> I knew that it was problematic because Dad told me, "We start preparing meals around five and we don't finish until after midnight. By the time we're finishing up cleaning the kitchen." Because seriously, they could no longer do more than one thing at a time.

Although her parents were still trying to maintain a degree of independence, Jamie had gradually noticed that they were no longer capable. Eventually she had to start preparing meals herself by the week, then delivering them to her parents' house so they would not have to spend so much time in the kitchen.

For Jillian, Stage 1 began when her mother stopped working. Since they were now spending more time together, Tina noticed small things that seemed trivial at the time.

> It started off with, "Oh yeah, I forgot about that." It's pretty normal, it's a phrase that all of us say. So we kind of let it go, but then we really started to pay attention when she'd say she forgot something. Something we just talked about. We would notice little things like that. [Then] she started to become really dependent on me. When we would go places she'd say, "No, you drive." And I just thought she wanted to be chauffeured around, and I'm cool with that. Then when I'd go to the store she'd say, "I'll go with you," and I'm thinking that she just wants to get out of the house. Everything, when we look back now, it was kind of the start of everything.

As is common in Stage 1, Jillian consulted other family members when she grew concerned about her mother's mental health. Her brother Ken, who has also been active in their mother's care since day one, recalled their collaboration:

> My sister was making note that my mother's memory was starting to be impacted…. I thought she was just losing her memory. Then my sister moved about five years ago, and that's when we really started noticing.

As Jillian and Ken's mother's condition progressed, her issues moved beyond dependence and into more severe memory and anxiety issues. Said Jillian:

> [She] took a really sharp decline. The faded memory got really bad. She was always asking a lot of questions, and she'd get really nervous, especially in the evening she would get nervous. Jittery, agitated. It was just weird. So we started going through the whole doctor's visits, checking this and checking that. At first they described it as dementia, and after that when they saw the MRI and all that they said that she had Alzheimer's. And it takes a while to get an actual diagnosis.

At this point Jillian had reached the final aspect of Stage 1, which is confirming. This involves getting an official medical diagnosis verifying that the CR does indeed have dementia. Not all CGs seek an official diagnosis, instead observing the symptoms of the CR over time and coming to their own conclusion that dementia is the cause. In this situation the CG is often correct that the CR has dementia, although without a medical diagnosis any further context or nuance goes undiscovered.

Stage 2

Stage 2 of the Three-Stage Model, *our life is changing*, takes place as the condition of the CR advances. In this stage, "families noticed on-going physical, psychological, and social changes in their relatives and they adopted a more vigilant attitude, observing the [CR] closely and keeping an eye on his/her activities and behaviors." This is an extension of the noticing aspect of Stage 2; the CR may be watched more actively, and the caregiving unit may do so discretely as to not alert the CR. The CR may still have a degree of freedom and self-sufficiency at the beginning of Stage 2, but as time progresses they begin to lose these capabilities and become more reliant on others (as exhibited by Jillian and Ken's mother not wanting to drive and Jamie's parents not being able to cook for themselves anymore). All involved in the care process may begin to internalize the fact that they will have to take on new responsibilities to maintain the wellbeing of the CR. Individuals may negotiate amongst themselves to determine the how to proceed, both for them and in the best interest of the CR. Family conflict may arise as all involved consult one another, and some may disagree on the best way to continue.

Kimberly's sister relocated over 1,000 miles to be closer to their parents when they were in need of care. Not all care requires such a physical reorganization, but sometimes rearranging family roles is necessary. Kimberly's young adult daughter, who had no prior care experience, was thrust into the position of emergency caregiver when the other adults nearby were occupied with work or other obligations.

> So if my husband and I were going out of town a lot of times she [their daughter] would be "on call" if you will. Be available, or go check on them. And then she would keep in touch with my sisters.

Even Kimberly's parents had to adjust; typically private people, they were forced to rely on those outside of the family for support. Kimberly's friend became an important point of contact.

> We also have a family friend that…over the years had developed her own relationship with my parents. Which was huge, because my parents were very much "if you're not blood, you're not family" types. And my husbands and I have a different approach, which is "a lot of times family is who you choose for it to be." And what's funny is that our friend became family, even in my parents' eyes, which was a huge thing. And because she was always around during a lot of family-type events anyway, Mom and Dad learned to trust her. And she was also backup.

During our interview Jermaine briefly touched on the family disagreements that can surface during Stage 2. He and his wife, Sherry, were both suffering from assorted ailments when they began having conversations with their children about relocating. Initially there was disagreement about how to handle the situation, exacerbated by the fact that one option presented by the kids was to merge households.

> It's family, so you have dissensions, you have arguments. Different, conflicting opinions on what should be done and when. So yeah, did it work out? Yes. Is it a whole lot better than us being stuck [alone]? Absolutely. But we liked our old house better than this one. It was an easy town to live in.

However, he and Sherry realized that due to their various conditions it was not feasible for them to live so far away from their children. In the case of an emergency, they had no family within hundreds of miles. Although they were not thrilled, Jermaine and Sherry sold their home and moved in with their daughter and her family.

Stage 3

Stage 3, *keeping things together*, revolves around the basic social process of balancing. As the authors state: "All families, to a greater or lesser extent, wanted to try and keep things together in the face of the constantly evolving challenges they faced. In doing so, families tried to simultaneously focus on providing the best care for their relative while at the same time preserving the personal, social, and working life of the family. This meant constantly adapting to changing daily events. Some families were able to do so more effectively than others who began to 'fall apart.'"

During this stage, caregiving units discover the best way to pursue caregiving based on their personal circumstances and settle into a routine of care. This is not to indicate that providing care is not stagnant; on the contrary, it may still be a tremendously dynamic process throughout this stage. However, the caregiving unit, for the most part, is past the negotiation aspect. Each individual involved has more or less settled on their responsibilities and the unit proceeds with this in mind. As opposed to negotiating and planning for the future, the caregiving unit is now in a more reactive phase; as the CR's condition evolves or worsens the CGs adapt accordingly. For instance, at this stage the caregiving unit may have decided that utilizing an ADC is the best option at the moment, and if the CR's condition worsens in the future they may consider nursing homes or other alternatives; however, for now the ADC is serving its purpose.

In Stage 3, some families achieve care-family balance, while others live in care-family conflict. Those who maintain care-family balance preserve "a positive relationship between caring and family life, with both activities being viewed as compatible and in balance with each other." Although they may have to make substantial sacrifices or adjustments to accommodate the caregiving career, those in this category are able to find and sustain enough positivity in their role so that the stressors associated with care are not overwhelming, e.g. despite spending three hours per day providing care, the CG is still able to fulfill all occupational obligations and maintain an active social life.

For Randy and Susan, going to Summit has allowed them to reach a stage of caregiving-family balance in their caregiving careers. Although they've had to adjust multiple aspects of their lives to accommodate the care of Randy's mother, neither of them feels that any reorganization is needed at the moment. Said Randy:

> She has not been combative or anything. So I think that would be the only way that we would probably look into something. She doesn't really wander that much, she has never wandered out front [of the house] or anything like that.

Barring a sharp change in Randy's mother's behavior, they will be able to maintain the balance they have established over the years.

Care-family conflict arises when, for whatever reason, the caregiving career is incompatible with some or all of the individuals involved in the provision of care. This may occur implicitly or explicitly, and the CG(s) may discover that they cannot deliver the time, energy, and resources necessary to provide an ample level of care. This is the point at which some caregiving units "fall apart" and must readjust; if there is anyone involved in the caregiving process who either does not pull equal weight or drops out altogether, the remaining member(s) decide on and implement a system that best fits the needs of the CR while maintaining as much normalcy and benefit as possible for the caregiving unit.

When April's parents moved in with her, she took on an enormous care responsibility. It was a bit easier when both of her parents were still alive, but following the death of her father her mother's condition worsened. A few family members stepped up momentarily, but eventually April was handling all of the care responsibilities herself despite having multiple siblings. April recognized that she was the only one who was willing to stick around through the entire caregiving process. "When you have someone in this condition you can't just dip and go when you want to. You've got to stay, you can't just drop out. My other siblings who live farther away can do that." April's siblings were not willing to adapt in order to ease the care-family conflict they were experiencing. However, they recognized that April was taking on the entire burden and thanked her profusely for her sacrifices.

> My siblings, they have their lives, but the one thing that keeps me going is that they thank me all the time for taking care of their mom. I need to hear that. I want them to acknowledge that, because no one stepped up to the plate when they needed somebody.

Brandi's situation sufficiently illustrates all aspects of the Three-Stage Model. Her father had been showing signs of early-onset dementia for a while, but these issues slowly became more prominent.

> Well I can remember the exact moment my mom told me he was having more serious problems. It had to be about…12 years ago. When you look back, we had noticed a few things that were slipping in his mind, like forgetting how to get to the store.

By this point, Brandi's father had developed issues such as hallucinations, difficulty recognizing family members, and incontinence. At this point Brandi and her family were in Stage 1. While not immediately suspecting dementia, Brandi and her family felt that her father was undergoing uncharacteristic changes in his daily life. As these issues progressed from relatively minor (forgetting how to get to the store) to serious (hallucinating and losing the ability to recognize those close to him), Brandi's mother informed the family of his difficulties before seeking a medical confirmation. "My mom got on top of it and got him on some medication… all we knew then was that they said he was diagnosed with Alzheimer's."

Upon the death of Brandi's mother, the family was thrust into Stage 2. Here, the remaining family members entered an extended negotiation with the CR and each other regarding the proper way to proceed. This process was especially difficult since neither Brandi nor her sister had been explicitly providing care prior to their mother's death.

> My mom suddenly died. We had only been visiting, like you do at a distance, maybe every couple of months and holidays. Brief amounts of time. It was fine. We probably didn't spend enough time with him [prior to their mother's death]… Looking back, I would've been a lot more involved if I had really understood.

Since their mother's death was sudden, no one had much time to prepare for the upcoming care need. Additionally, they were not completely familiar with the day-to-day needs of their father and the effort required to maintain his wellbeing. Brandi recalls:

> We didn't really know who we were dealing with. At a distance, we didn't know. Does he leave, does he wander? Do we have to worry about him? Is he going to kill himself in his house if he's left alone? So we never let him stay in his house alone again. It was a real abrupt change.

As her family progressed through the second stage of the Three-Stage Model, tensions arose between the major figures: Brandi and her sister. Brandi was much more accommodating to her father's needs, while her sister was not willing to adjust her hectic calendar. Due to Brandi's more adaptable schedule and the ability of her husband to help out, their father ended up staying with her. For Brandi, providing care was a more salient responsibility than it was for her sister, so she was more willing to concede.

> [My father] came to my house. I had a small house at that time. And he stayed for I think a couple of months. My sister maybe watched him for like a week and a weekend or something, because she was very…she was pursuing a whole new career, she was getting a graduate degree. And it was very demanding. So it was bad timing for her. I had a job, but I had more flexibility. And my husband, he was in the oil field, so you come and you go. You can sort of work it out. And he was doing some contract work anyway, so he was home.

After a few months the family decided to try out an assisted living facility to ease the weight on Brandi and her family. With a husband, two children, and a relatively small home, coupled with the unexpected timing of the caregiving career, she was somewhat overwhelmed with the situation. Although Brandi's sister only lived an hour away, she was unwilling to help look after their father. Brandi recalls the events as she discusses the early stages of providing care:

> She stopped bringing him to her house because she said these two things: She said 'I can't have my furniture ruined," instead of just finding a solution. And he likes to go outside and smoke, and they lock the door with a key at night, and she didn't want it unlocked. He would set off the alarm. So that's the kind of person she is. She's too rigid.

The assisted living facility did not work out as planned. After staying there for a couple of years, the family felt as though their father had been "forgotten about" by the staff. Brandi recalls that the facility was not specifically a memory care center, and that perhaps they were not equipped to accommodate his precise needs. Since assisted living does not explicitly include 24-hour aid, issues such as her father's incontinence went unchecked for hours or days at a time. "We made a lot of mistakes early on. Assisted living is really like living alone in your apartment." Brandi continued:

> Once you shut that door they leave you alone. And his biggest problem is incontinence. So you'd go over there and it would smell just *horrible*. And we would be like "What is that smell? Why is it here?" And they couldn't tell us.

Her father's physical health also seemed to be deteriorating in ways that were not present prior to the change.

> It was a really nice place, but things started happening. He started losing a lot of weight. He wasn't coming to eat with them anymore, and I think his social life just kind of took a dive. He just didn't seem…it seemed like he was just existing. Not much of a life.

Her father's time in assisted living can be considered Stage 3 of the Three-Stage Model, since the caregiving unit had reached a point of relative balance and equilibrium for all parties involved in care provision. However, upon realizing that his needs were not being met, the family had to revert back to Stage 2 and redefine the process of care. Since assisted living was not working, Brandi's family and her sister's family had to go back to the drawing board to figure out a new plan.

It was actually Brandi's husband who suggested that they buy a bigger house and bring her father back in to live with them. Once again, negotiations had to take place within the caregiving unit to establish the best possible scenario. Both Brandi and her husband were working full time, but Brandi's husband was able to alter his schedule and work from home most days. Brandi recalls, "he said, 'Why don't we just buy a house and we all move in together? I'll stay home. I'll take care of him, you keep your job, and we'll see how that works." Brandi was thankful that her husband was willing to make this concession since providing 24-hour care would not have been possible otherwise. While her father is self-sufficient enough to handle some activities of daily living, he cannot be left unsupervised for more than a couple of hours at a time. At this point, Brandi and her family have reentered Stage 3 of the Three-Stage Model, and all involved have achieved balance. Brandi's sister has a balanced life since she does not have to inconvenience herself to provide care. Brandi's household has achieved balance because they have a home large enough to accommodate more people, Brandi is still able to work, and her husband has realigned his schedule to provide daily care. And Brandi's father is receiving better and more consistent care than he was in the assisted living facility.

Through the framework of the Three-Stage Model, we can better understand how the caregiving career progresses and why family caregiving units operate the way they do. With this in mind, I will specifically analyze Stage 2 of the model: what are the patterns of help-seeking among those in my sample? Specifically, I will investigate how CGs navigate formal and informal networks when determining ADC use. But first, I will examine other factors, on both the macro- and micro-levels, that may impact whether or not a caregiving unit utilizes ADCs.

ECONOMIC AND SOCIAL CLASS FACTORS INFLUENCING ADULT DAY CENTER UTILIZATION

The average age of an ADC recipient is 72 years old (NADSA 2017), and they come from a variety of living arrangements:

Characteristic	ADC recipients who meet criteria
Live with an adult child	35%
Live with a spouse	20%
Live in an institutional setting	18%
Live with parents or other relatives	13%
Live alone	11%
Are women	66%
Have some cognitive impairment	52%

Table 8: Characteristics of ADC Recipients (National Sample) [Source: NADSA (2017)]

However, CGs who do not utilize full institutionalization (for whatever reasons, not just financial) are in the strong majority. In 2006, approximately 70% of those with Alzheimer's lived at home, and 75% of their care is provided by family and friends (Earle 2006; Simpson & Acton 2013). With such a large proportion of care provided informally, ADCs seem like a fantastic complement to the caregiving career that allows CRs to remain at home for as long as possible. With the relatively low levels of participation, however, questions arise surrounding the structural and individual-level factors influencing this trend.

An important question regarding ADC utilization is also a very basic one: How do people pay? According to NADSA (2017), approximately 78% of ADCs are operated on a nonprofit or public basis, while the remaining 22% are for profit. Daily fees may vary depending on the services provided, but the average rate is $61 per day (Summit's daily cost was $60; by comparison, the average rate for a home health aide is $19 per hour). This cost varies by location; some facilities in Alabama are as low as $29/day, while in Vermont ADCs can cost as much as $148/day. (MetLife 2011) Many centers offer services on a sliding scale, and although it is typically far cheaper than other care options, in some states Medicaid covers the cost of for people with low income and few assets. (Alzheimer's Association 2017a). In the case of Summit, those who qualify for Texas Medicaid, Veteran's Administration (VA) Benefits, or who have private long-term care insurance have their costs fully covered. When paying through third parties such as the VA, CRs are not authorized for benefits until the organization's doctors evaluate them and they are deemed eligible. One CG described the series of tests that her husband had to go through before being authorized for funds: "The VA is paying his whole bill [at Summit]. So he had to go through some VA evaluations also. They're not going to pay it unless they do. And he failed all of the evaluations, but I knew he would. I didn't even have to say anything. So he's been through that series of doctors too." In this case, the CR failed all of the evaluations of cognitive aptitude presented by the doctors at the VA, so he was deemed eligible for assistance due to his condition.

Due to the disparity among ADCs (public vs. private, differing policies state-by-state, etc.) the method of payment varies. Payment may be measured on an hourly, daily, or monthly basis. For example, at Summit, the $60 daily cost covers any amount of time spent at the facility. Those who only come for a few hours in the afternoon pay the same cost as those who are there for a full 10 ½ hour workday. Nationally, over 80% of participants attend full days at ADCs and 46% attend five days per week (NADSA 2017). Beyond the standard rate, other additional charges may include meals, snacks, transportation, outings, and ancillary services. All of these services (excluding outings) were included in the daily rate at Summit; on the occasions where members were taken to the movies or to some other event that required payment, the member was required to bring their own money that day or were not permitted to attend.

Access to resources influences the likelihood of using informal care or instead opting for institutional care. Resources include anything an individual or family unit has at their disposal to aid them in the caregiving process: income, wealth, time, social ties, etc. The type(s) of resources that the individual or family has the most access to will weigh strongly on the form of care that is provided. For instance, those with great wealth or income may be able to fully institutionalize a loved one without jeopardizing the financial stability of the family, while those without this luxury cannot afford to do so. On the other hand, those who have social networks who can provide care for free may not have to spend any money at all, instead relying on friends or family. Roberto, whose wife suffered from cognitive decline, behavioral fluctuations, and severe mood swings for years, needed a special institution equipped with trained staff that could handle her condition. No acquaintances were equipped to assist in her care since it was so drastic. As a relatively affluent household, Roberto was able to find an institution that fit his needs very close to his neighborhood: "It's right down the street. It's a very nice facility. I will tell you that it's extremely expensive. The facility she's in is $5,000 a month. That's a lot of money." Such services are not as widespread as general nursing home or assisted living facilities, and they tend to be located in more affluent areas. Additionally, Roberto has the economic resources that allow him to spend $60,000 per year on her housing, excluding additional expenses such as medication.

Unlike the social democratic regimes found in other parts of the world, especially Europe, the United States is a liberal welfare regime with fewer structural supports available to its citizens (Cooke & Baxter 2010). Because of this, much of the full institutional care that is required for those with dementia is most readily provided by private entities instead of state-sponsored ones. Programs such as Medicare may offer provisions to those who qualify so some of their ADC costs are offset, but this is not a guarantee for all. Families are left to cover the remaining cost if their CRs cannot receive full assistance from such state or federal agencies.

Private, formal care providers are growing in popularity, but most that provide total care for IWD are too expensive for the majority of families to realistically consider (Bookman & Kimbrel 2011); even including those who are not suffering from dementia, fewer than one-third of older Americans perceive that they will be able to independently finance three or more years of long-term care for themselves or others (Wolff et al. 2008). Because of this, ADCs may be a more appealing option for individuals whose family units can provide some, but not all, care for their loved ones.

Because facilities that specifically cater to individuals with dementia can be especially costly, this dynamic of institutionalization creates three tiers of care for upper class, middle class, and working class families. Upper class families may be able to afford institutionalized care without jeopardizing their lifestyles. Middle class families may or may not be able to afford institutionalized care, but even if they can it may put a significant strain on their finances; ADCs are often the most realistic option. Working class families almost certainly cannot afford to send anyone to a total care facility, but certain accommodations may be available for those who qualify for Medicare.

The structural economic factors of aging may determine who even makes it to old age. Many disadvantaged people die before they reach advanced ages, as the mortality gap in social class remains persistent (Abramson 2015). Lower status people die sooner, and they are less healthy when they are alive. Those with better access to economic capital have greater ability to age in senior communities with robust social services. Residential areas with senior-friendly built environments (such as transportation services that are available, accessible, acceptable, affordable, and adaptable) may not be spatially evenly distributed (Kerschner & Harris 2007), as they are more likely to be found in affluent areas.

Tina has experienced many caregiving situations in her life. Besides currently caring for her husband, multiple older family members have needed similar assistance in the past. She recalls having to take in her father-in-law early in her marriage, and she believes the experience had a negative effect on her three children. Their grandfather acted erratically and was prone to mood swings. These issues were magnified by the fact that they lived in a rural area with a severe lack of services available to families with caregiving needs. "All three of them remember the grandfather situation. How horrible that was. And when you're in [a rural area] there are not many facilities." Perhaps a community with more structural supports would have been able to support Tina and her family through their difficult times, but instead they were forced to turn inward and take on the responsibility alone.

OTHER POTENTIAL FACTORS INFLUENCING ADULT DAY CENTER UTILIZATION

There is clearly a need for caregivers in the U.S., and adult day cares are growing in quantity. But beyond social class influences, the question still remains: why are there so many families from across the economic spectrum who provide some or all care themselves, without the use of any eternal services or interventions? And why do some groups have higher rates of utilization than others? The origin of some of these patterns may be rooted in factors such as culture, race/ethnicity, and gender.

Andersen's Service Utilization Model (Werner et al. 2014) posits that there are three factors that determine utilization of any intervention or long-term health service. First are predisposing factors, such as age, race, culture, and belief in health benefits (i.e. a person who believes that health services are effective is more likely to seek care). Andersen's second determinant is enabling factors, such as family support, one's community, and health insurance. In the presence of available services, such entities make it easier for an individual to find and utilize them. The last factor is need, both perceived and actual. When an individual believes that care is urgent, they are more likely to seek it.

An example of a cultural explanation for ADC underutilization is the collectivist vs. individualist ideology. Burleson (2003), researching cultural outlooks, identified these two different value systems. While they are two extremes on a spectrum, conceptualizing these ideal types helps us to theorize about the differences in value orientations of different groups. According to Burleson, those who hold a collectivist ideology find more pride in the wellbeing of the group than they do in their own personal accomplishments or goals. These individuals may put the needs of the larger social group ahead of their own desires.

On the other hand, those who hold a more individualist orientation are more likely to pursue their own goals ahead of those designated by the group. These individuals find more satisfaction through self-fulfillment than they do through communal accomplishments. For instance, it could be argued that historically women have more often been socialized to adopt a collectivist ideology than an individualistic one, which would contribute to the feminization of care that we observe to this day. Additionally, this concept can help explain why informal care is more common among certain racial/ethnic groups (Lan 2002; Williams & Barton 2003; Fingerman et al. 2011).

Nativity status can also play a part in cultural outlook; for example, even in relatively dire cases, foreign-born Latinos are less likely to use nursing homes and home health services, primarily relying on family and friends for assistance (Angel et al. 2014). These individuals may operate on a different set of (more collectivist) norms and values than native-born Americans do.

Women make up the majority of both Alzheimer's caregivers and ADC recipients; about two-thirds of the 15.9 million unpaid family caregivers in the United States are women, and roughly two-thirds of all ADC recipients are women (Alzheimer's Association 2016; NADSA 2017). Beyond the gender component, multiple additional factors influence one's likelihood of becoming a caregiver: being unemployed, living closer geographically to the care recipient, and being an only child or having fewer siblings (if the care recipient is a parent) are all associated with higher probabilities of caregiving (Dautzenberg et al. 2000).

Additionally, there are racial and ethnic patterns in who is most likely to provide informal care to their family members. Asian Americans, Latinos, and African Americans are the most likely to rely on friends, family, and/or neighbors, with African Americans being especially likely to utilize kin and give support to parents, even when controlling for resources and demands (Bookman & Kimbrel 2011; Fingerman et al. 2011). This may be due in part to the fact that members of racial minorities are more likely to report perceptions of discrimination in healthcare settings (Abramson et al. 2015), so they may feel less comfortable placing family members in ADCs or nursing homes. Additionally, racial/ethnic minorities may have stronger cultural and personal attitudes endorsing assisting parents or maintaining a collectivist familial orientation (Fingerman et al. 2011).

Brandi attributes the way she approaches caregiving to her collectivist cultural upbringing. Her mother's side of the family is of Hispanic origin, and their outlook on kinship left a lasting imprint on her. She believes that ethnic culture, not just hers, has a sizeable impact on how different groups provide care.

> In my experience, I grew up in a half-Hispanic household. My mom and all of her family, we grew up around all of them. It’s a cultural thing that I think differs from a lot of other cultures. I think there’s, for instance, you hear that Asian people really take care of their elderly population very well. But I can remember that my mom always said “We don’t leave our family members in a health crisis.” This is what you do. You take care of family.

She cites this as a major reason why she has embraced her living situation with her father. Although her sister also grew up in the same household, Brandi believes that she internalized the collectivist aspect of her culture more. According to Brandi, “[her sister] has a lot more care and concern for her clients, strangers, church people, than she does for us.”

Russell, who is of Indian descent, also feels like his collectivist culture and upbringing shaped how he is providing care. His mother came to the United States from India to live with him when she started showing signs of dementia. She was becoming defiant, wandering away from home, and getting lost in the city regularly. Due to her family situation at home, there were no sufficient services available to aid Russell’s elderly father in providing care. The nearest elder care facility was in another city, and the family had no relatives there.

After multiple trips to the other side of the world to remedy various issues, Russell decided to bring his mother back to the United States with him. He spoke about how his decision to take his mother in was not unusual given his background:

> For the most part people with dementia and old people, traditionally in Indian society people live with their kids. That's the way people deal with it. I guess people had dementia for a long time, it's just that nobody ever talked about it. It's just like, "Okay, she's weird or she's eccentric.” You just put up with it and life

> goes on. Growing up in India you always feel a duty to care for your parents. My grandmother was taken care of by my aunt as she grew old. My dad's sister, for example, took care of one of his other siblings who had polio and was bed ridden for many years before she died. It's kind of like I've seen it in my family and in everyone else's family.

Coming from a household with a collectivist familial orientation, neither Brandi nor Russell hesitated to take their parents into their homes. Both of them were also hesitant to fully institutionalize their parents. Since they were in a relatively balanced phase of their caregiving careers, Brandi and Russell’s collectivist mindsets contributed to their decisions to work out arrangements where their parents would be able to stay at home for as long as possible; Russell utilized ADCs while the adults in Brandi’s household took on new roles to accommodate her father’s situation.

Associated with this trend is the stigma of formal public care; while not only associated with racial/ethnic minority populations, research suggests that this trend is associated with those who subscribe to a collectivist orientation, such as ethnic Chinese immigrants in the United States (Lan 2002). In this scenario, even though entities such as ADCs or senior centers may be available, families choose to pay for private care in their homes or shun external assistance altogether because they view public care as stigmatizing. Public care does not necessarily refer only to state-funded bodies, but also those that are ‘public’ in their operation, i.e. taking place outside of the household. Using services that take place in the public sphere allow the CR’s condition to be observed by others outside of the family, which may bring a degree of shame or embarrassment to some or all involved. Additionally, having the ability to provide care within the household (either on their own or by utilizing home health services) may be a status symbol for the CG, since their efforts allow the CR to age in their homes instead of a public arena.

April, who is the only sibling providing explicit care for her mother, also stated that her outlook on the importance of family drew her into the caregiving career. Her collectivist mindset is strongly attributed to religion, and also prevents her from fully institutionalizing her mother unless there are no other solutions.

> I know a lot of people who don't like caring for the elderly, and I'm not going to sit here and say that I love it. But I'm doing it because it's the right thing to do. I just can't see me letting them go to a nursing home. I had a cousin ask me why I didn't just put them in a nursing home. No, I'm not going to do that.

April also acknowledged that caregiving was not something she ever envisioned doing, but she also felt it was her responsibility, based on faith, to step up for her mother in the face of adversity.

> Yes, it changed my whole life. Seriously, no telling what else I may be doing. But then again, God did this for a reason. I always say that. Because it could be something worse going on with me if I didn't have my parents. Everything is done for a reason, I truly believe that. So you accept it and go on. I'm fine with it.

PATTERNS OF HELP-SEEKING AND PATHWAYS INTO ADULT DAY CENTERS

As explored in chapter 1, very few CGs utilize ADCs as an intervention to aid in their caregiving careers. There may be multifaceted structural factors influencing this pattern: ADCs are not geographically evenly distributed, costs may be too high, or CRs may not qualify for benefits that would allow them to afford such services. However, in this section I explore another potential reason why ADC use is so low: the relationship between formal and informal help-seeking. Formal help-seeking is the process of seeking assistance, support, advice, or treatment from professionals (primary physicians, etc.), while informal help-seeking refers to the process of seeking help and support from the social network, including family members, friends, and neighbors (Werner et al. 2014). Informal help-seeking also includes knowledge that the CG receives through independent research or other means (online searches, pamphlets, advertisements, books, magazines, newspapers, etc.).

Previous research has explored help-seeking behaviors of both CGs and patients (Pescosolido et al. 1998; Hamilton-West et al. 2010; Carter-Harris et al. 2014; Werner et al., 2014; Gözüm & Tuzco, 2017); however, this section of my study applies the ideas of formal (i.e. seeking information from doctors and other medical professionals) and informal (i.e. seeking information from friends, acquaintances, online sources, books, etc.) help-seeking specifically to the case of ADCs. Throughout the interviews I conducted and based on my observations at Summit, I identified a trend that I refer to as *Echoed Help-Seeking*. Though the process for other types of interventions may differ, when exclusively analyzing respondents who utilized ADCs a consistent pattern of help-seeking, characterized by three events, was revealed: 1) initial informal/independent help-seeking; 2) formal help-seeking; and 3) a reversion to informal/independent help-seeking that eventually leads to the discovery of ADCs.

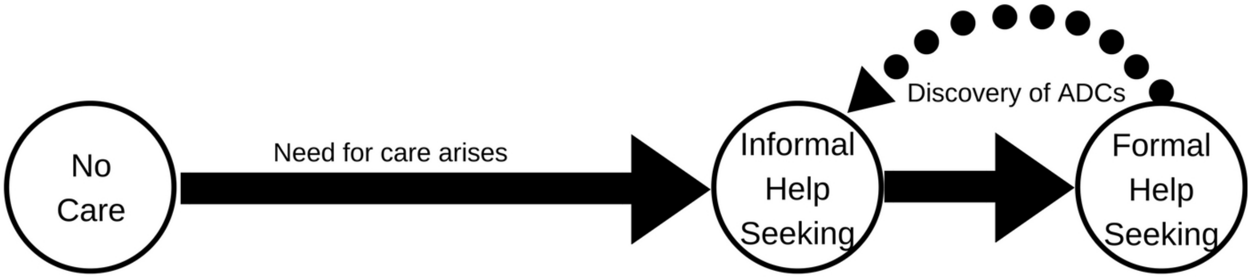

Figure 3: Echoed Help-Seeking and ADC Discovery

Echoed Help-Seeking is a process that takes place within the first and second stages of the Three-Stage Model. While the caregiving unit is still in the process of observing, evaluating, and weighing their options for the future, this manner of help-seeking takes place for those who ultimately choose to use ADCs.

Also, the model does not suggest that CGs no longer utilizes formal networks upon their discovery of ADCs, nor does it suggest that general formal or informal help-seeking ceases at any point in the process after it has begun. It simply illustrates how the discovery of ADCs typically does not happen until after interactions with formal entities, and only from informal networks. CGs are most likely indefinitely interacting with both formal and informal networks once each of these is tapped, but ADC discovery comes by informal means following formal help-seeking.

STAGES OF ECHOED HELP-SEEKING

Event One: Initial Informal Help-Seeking

Overall, 10 of the 20 interviewees for this project either currently utilized ADCs or had used them in the past. A common thread among these 10 CGs was that when signs of dementia first occurred, each of the respondents consulted informal networks such as relatives and friends; this is *Event One*. As discussed in the context of the Three-Stage Model, at this point CGs may attempt to handle caregiving responsibilities on their own or take a “wait and see” approach to observe how the CR’s condition progresses. CGs may consult family and fill them in on the cognitive decline of the CR, as well as seeking advice or other input on the best way to proceed. This finding is supported by Werner et al. (2014), whose review of help-seeking literature found that the general consensus within the literature is first seeking help from close relatives (mainly spouses and children), followed by branching out to primary health professionals such as family physicians. Additionally, during this event the CG often speculates about the trajectory of the CR’s condition and where it may lead in the future.

Christy’s father, who lived in a senior community, was getting to a point where she was concerned about his cognitive health. Although Christy lived in another state, she would contact her sister-in-law, who lived closer, to check in on him periodically. After observing his condition for a while, they consulted each other to try to figure out the best way to proceed. The situation was manageable at the time, and Christy’s sister-in-law would handle various day-to-day tasks. Christy recalls, “My sister-in-law who lived in the area, she’d go over once a week. Help him balance his checkbook, socialize with him.”

However, research by Walker et al. (2017) also expanded on the limited nature of these methods. Although personal networks are widely used (and often preferred), they are not the most efficient means of gathering information. Although CRs turn to friends, neighbors, acquaintances who have dealt similar circumstances, and religious organizations for help, these networks alone are not always sufficient. CGs recognize gaps in information, often “believing that organized information exists that they simply cannot find.”

Event Two: Formal Help-Seeking

For those who still need assistance or interventions, they must move beyond Event One. Following this period, the CG moves to *Event Two*, seeking formal assistance from physicians or other care professionals. Event Two takes place at the tail end of Stage 1 in the Three-Stage Model. The elapsed time between Events One and Two vary based on the severity of the CR’s condition and the CG’s ability to manage care responsibilities. For Christy, it was years before she and her sister-in-law felt that it was time to branch out and speak to someone. She spoke to the social worker on staff at the senior living community, and after closely monitoring Christy’s father for a period, the social worker began “talking to be about her concerns about him needing more support.”

It was then that Christy sought out medical professionals to inquire about his possible dementia symptoms.

When consulting a physician, CGs obtained an official diagnosis and typically received a medical intervention (pills, etc.) to alleviate the dementia symptoms; most CGs noted that this was the first (and sometimes only) possible solution or intervention suggested by their doctors. A number of CGs welcomed this solution as a way to curb the CR's cognitive decline and/or mood fluctuations. Jillian and Ken's mother, who would experience drastic behavior changes at dusk due to Sundowners, showed improvement upon receiving a medical intervention. Ken recalls, "Her core behavior, thanks to medication, stays about the same. But we do have instances where she's working herself up into a cycle." While it did not solve all of their problems, medication helped them manage their mother's situation more easily. Jillian reiterated this sentiment:

> Once we got her on a certain level of medication it calmed down slightly. And it wasn't until they put her on the Namenda and the Aricept, which are the two medications they put Alzheimer's patients on in tandem, that we really started to notice that she calmed down. She could function better. It's not clear, nothing's ever clear, but you can give her simple commands. "Mom, put that shirt on. Let's brush our teeth. Do you need to potty? Would you like a drink of water?" You know, simple things. She can focus on small tasks.

While interventions such as pills certainly help many CGs, some of those in my sample felt their doctors were either 1) unable to suggest any other solutions or interventions due to lack of knowledge, or 2) that the doctor viewed pills as a catch-all solution. Tina, whose husband experienced a sharp decline in ability, was frustrated with the medications' lack of effectiveness.

> You name it, he's done it. Nothing changed anything. Nothing. I've never seen anything work for anybody. We did try Aricept, and it didn't do anything. The

> other one, I can't remember the name. But we tried that. And it made him super confident. "I can do anything, I can drive a car!"

As Tina noted, not only were some of these solutions ineffective, but they also had unwanted and unanticipated side effects. In her opinion, prescribing pills as a first impulse is lazy and uneventful. "I just feel like the medical community is missing out, sending people away with pills. I don't think that's always the answer."

Due to side effects and other reasons, a number of interviewees revealed that they had chosen to curtail or eliminate the CR's consumption of medication altogether. Christy's father was having serious side effects that were making his life difficult, all while having minimal positive impact on his dementia symptoms. Christy spoke about the changes she had made to his medications since he had moved in with her and her family:

> Since he's been here he's gotten off of a lot of them. At one point he was on something for his urine, he was urinating too frequently. And he was on a couple of dementia ones. But he used to hallucinate more and say, "Who's that sitting on the couch?" Or he'd see people in his bedroom. And I'm reading all of the possible side effects of some of those medicines and I was like, "Can we try not taking these things? I don't think they're helping." So he's been better.

Christy ended up eschewing as many medications as possible, instead deciding that her father's current quality of life was improved by using other strategies to mitigate the effects of dementia.

Chelsea, who cares for her parent and spouse simultaneously, spoke of the balancing act involved with prescription medications for her mother:

> I'm not a medical person, but I'm a human who thinks and has learned a little about these conditions, Alzheimer's and dementia, and their medications. The medications, if they work, it doesn't necessarily mean that they'll work really well. They might work a little bit. You always have to weigh the pros and the

> cons. What are the costs of taking these medications versus how much it's actually going to help?

Additionally, she considered the adjustment period associated with many of the medications her mother's doctor had suggested.

> If it's only going to help a little bit, and she has to be miserable for two months, and I have to be miserable for two months, knowing that I also have someone else to take care of plus my own things, is it worth it? So I didn't give it to her. But the main reason was because it might affect her heart. So I said no, I'm not messing with something that might affect her adversely in the most remote way. So I didn't give it to her.

Katharine's CR, her mother, does not live with her, but Katharine still maintained all of her mothers medications. She was concerned that different doctors may prescribe medications without familiarizing themselves with the current ones that the CR is already using. Some doctors may not have access to records from other offices; even if they do, some doctors do not thoroughly examine them. Thus, there can be conflicting opinions or goals among the various doctors for one CR. Luckily for Katharine, she has a close friend who is also in the medical field who was able to take a comprehensive look at the list of medications being used and offer a dissenting opinion.

> Well that's why I contacted my doctor friend. They said, "Your mom shouldn't be on two antidepressants, and she shouldn't be on this other thing because they shouldn't even give it to people over 80." I talked to her psychiatrist, he wouldn't put her on these memory things that are supposed to make your memory better. He said he doesn't like to prescribe them, but [the CR of another CG I know] is on them and they said that it made a huge difference.

Katharine was able to get a solid judgment from a medical professional that she trusts, rather than fragmented opinions from her mother's numerous doctors.

> I'm really glad my doctor friend was able to look at these medications, and I'll probably pursue it further. They came in and did an evaluation of my mom about

> three years ago as well. It's kind of hard when you've got different doctors who do different things. They're supposed to have a list of all of the medications.

As beneficial as strictly medical interventions can be for CGs, in my sample it was essentially unheard of for doctors to suggest much else. If there was a discussion of other options for assistance between the physician and CG, it revolved around nursing home care or other forms of full institutionalization, such as assisted living; ADCs were not discussed. Respondents spoke of being wary of full institutionalization for a number of reasons, such as the tremendous cost often associated with these options. Respondents also commonly reported that at the time they felt like they were managing caregiving fairly well, and that while they may have still needed assistance they were not quite ready for such a permanent option. Following this formal help-seeking action, CGs continued to provide care for the CR without utilizing full institutionalization.

Event Three: Return to Informal Help-Seeking

Event Three involved receiving knowledge of ADC services from an informal social tie. Only one of the 10 respondents could not recall how they discovered the ADCs; each of the nine respondents who recalled their initial introduction to ADCs reported that they received this information through informal means or networks. Importantly, each of these instances took place *after* the CG had already sought formal assistance. Generally, respondents reported that the options they had discussed with physicians did not meet their needs at the time, but ADCs were a better fit for their current situations. Of the respondents who recalled their discovery of ADCs, five of the nine were informed of ADCs by family members or neighbors, two of the nine found ADCs after researching independently, and the remaining two saw fliers for the ADC at a community center and subsequently inquired about it.

#	Respondent	How did they learn of ADCs?
1	April	Does not recall how she discovered ADCs; believes it may have been a doctor or acquaintance, but remembers that she did not search for this information herself
2	Jillian	(Sister of Ken) Was informed of Summit by an acquaintance of the family
3	Jermaine	Discovered ADCs after his adult child did research online to find a better caregiving option
4	Ken	(Brother of Jillian) Was informed of Summit by an acquaintance of the family
5	Lisa	Her sibling did extensive research online and discovered that there was an ADC in their area; Lisa had done online research before but had never come across the same results that her sister did
6	Randy	(Husband of Susan) Was utilizing another senior center for daily care, although it was not working out ideally; while at the senior center one day, saw a flier advertising Summit
7	Roberto	Has a relative who is a social worker; after using their knowledge as a social worker to do some research, discovered that there was an ADC in his area
8	Russell	Discovered Summit through is own research when trying to find at-home caregivers for his mother
9	Susan	(Wife of Randy) Was utilizing another senior center for daily care, although it was not working out ideally; while at the senior center one day, saw a flier advertising Summit
10	Tina	Searched on her own for alternative sources of care as her husband's condition became too much to handle alone

Table 9: Respondents Who Utilize ADCs and How They Learned of This Intervention

It must be noted that there are two pairs of CGs for the same CR in this sample: Ken and Jillian both care got their mother, while Randy and Susan care for Randy's mother. In both cases, all parties were thoroughly involved in the formal help-seeking aspect of the CR. At various times, each CG would interact with formal medical authorities (they would either take turns going to appointments, go to appointments together, or split the responsibility based on availability and other obligations). Despite this, none of these four CGs ever had a conversation with a medical professional about the existence of ADCs or the CR's candidacy for such an intervention. In both cases, the caregiving duo learned of Summit through some other means and pursued it on their own.

WHY DO MANY CAREGIVERS DISCOVER ADULT DAY CENTERS THROUGH INFORMAL PROCESSES, EVEN AFTER CONSULTING FORMAL HEALTH SERVICES?

Most respondents speculated that their physicians were unaware of ADC services at the time of their initial formal help-seeking actions, but there is evidence that in some cases physicians simply did not inform the CG of such interventions. For example, Jillian, who found out about ADCs from a neighbor, recalled how their physician told them about Summit months after they had enrolled their mother there:

> [My neighbor] was the one that said, "You know, there used to be this place," and this was back when Summit was in a different location. It was actually called something different, but she remembered them when they were there. She said, "You need to find them, contact them, and see if they still do the adult day care," and that's how we found it. But it wasn't after we already had her enrolled and she'd been there four months, we had an appointment with her primary doctor and they're like, "Where does your mom stay during the day?" I said that she was at a day care center, and she's like, "Oh, Summit?"

In an exasperated voice, Jillian continued, "I was here four months ago when you diagnosed her and you couldn't open your mouth and said Summit? Thanks." Although laughing throughout the recitation, Jillian was clearly still taken aback by the exchange. The doctor, who was undoubtedly familiar with Summit, had not brought it up to the family despite being their physician for years beforehand. This supports the suggestion by Schulz & Eden (2016) that in some cases, physicians do not properly identify CGs as good candidates for interventions that would be useful to them.

Additionally, these findings are consistent with the NASEM Report (2016), which suggests that despite their importance in the maintenance of the CR's health, family caregivers of older adults are often marginalized, if not ignored, by care providers and medical professionals. The delivery of care, especially to older adults, is often fragmented; there can be little or no coordination between physicians and long-term services and support entities. Tina recalled that her husband's psychiatrist's advice at the beginning of her caregiving career: "I took him to a neurologist, who referred him to a psychiatrist. MRI, a whole bunch of stuff. And the psychiatrist said, 'You're going to have more problems with the medical community than anybody.'" She was frustrated by their seeming lack of interest in learning anything about her husband beyond their precise specialization:

> I'll tell you this. I've gone through two sets of doctors, and not one of them has ever asked the backstory. You'd think they'd try to be gathering data, even if it's 10 questions. Did he box? Did he play football? Whatever. Nobody's ever asked me the backstory. Never. So there you go, there's the medical community. You'll have your focus, but the neurologist is really focusing on Lou Gehrig's disease. He saw us, but really he wasn't interested. But I've learned from the two doctors [in the family] that they only have a very narrow focus, very specific knowledge. They don't know all that much beyond it.

In Tina's experience, doctors were invested in her husband's case as long as it had an explicit link to their specialization, so no individual doctor as a full understanding of his condition. This lack of synchronization and shared understanding can lead to gaps in knowledge from all parties involved.

CGs may not know which questions they should even ask during doctor's appointments. People seeking advice about medical treatment options, especially those who are "first timers," often "muddle through" the process without full knowledge of where they are headed or what information they are supposed to know (Pescosolido et al. 1998). CGs in this situation may not realize that there are further options available, relying on the words of their physician to fill in the blanks. Indeed, many families "feel underprepared for aging-related challenges and face obstacles with care coordination with clinical teams" (Adelman et al. 2014). Furthermore, care providers such as ADCs may not effectively communicate the availability of their amenities to locals, and doctors may be unaware of the full range of services and interventions accessible to their patients. Only one-third of CGs report that a doctor, nurse, or social worker had ever asked them about what was needed to care for their relative (NASEM Report 2016). If medical professionals are not well-versed in the dementia or the full gamut of interventions available, it can leave the CG in a vulnerable position. As Jillian recalled following her first visit to the doctor with her mom, "When you go to the doctors they have a little bit of information, but it's not like anybody gives you a 'Welcome to Alzheimer's' packet. Here's everything you need to know, everything you need to plan. You have to figure it out all on your own."

A physician's ability to systematically identify the best interventions for CGs and CRs is a key component to providing full, proper care. Levkoff's help-seeking model for dementia (Werner et al. 2014) emphasizes the importance of contact with care providers in the effective discovery and utilization of the proper social services and interventions. When the physician does not present all available options to the CG, patterns of Echoed Help-Seeking arise. CGs are more likely to either 1) consciously go back to informal strategies since physicians seem unable to help, or 2) continue to utilize informal strategies in conjunction with advice from physicians. Furthermore, CGs are more likely to frequently access informal means of help-seeking. An Internet search, conversations with friends, or phone calls with family members are relatively simple and common occurrences, so the exchange of information is more frequent. For example, Kimberly recalled that, "people would always send me stuff saying 'I heard about this' because they knew I was looking for things to learn [about dementia and dementia care]."

Conversely, doctors visits may be few and far in between, exacerbating the potential rift in the exchange of knowledge.

Since the physician is the individual who is expected to provide knowledge of these entities, CGs may feel like they are being cheated when they discover that they were not fully informed of their options by formal institutions. However, from the physician's perspective, there are difficulties and barriers associated with this process. For instance, research from Halpin et al. (2017) explored the dynamic nature of doctor's visits in the context of dementia. In the case of cognitive decline, CRs may experience tremendous fluctuations in mood, temperament, and accessibility. The CR may act differently during a doctor's visit due to the unfamiliarity of the environment, making it difficult for the physician to accurately assess their state. Situations such as this are ripe for misguided or nonexistent interventions by formal support.

Even outside of a medical context, assessing the state of an individual with dementia symptoms can be a formidable task. For example, research by Ranchet et al. (2017), exploring data from road tests by IWDs, found wide disparities in the perception of the individual's abilities. In this study, "68 dementia patients underwent medical, visual, and road tests at an official center of the Belgian Road Safety Institute." Following the tests, both physicians and on-road assessors evaluated the drivers and made fitness-to-drive recommendations using one of three categories (favorable, reserved, or unfavorable). Results showed that physicians, as opposed to on-road assessors, were 35% more likely to overestimate the patient's fitness to drive and 22% more likely to underestimate their ability. Additionally, those who incurred the most traffic violations were more likely to be overestimated by the physician. Overall, results indicate that even when observing the same behaviors, physicians may not always be able to pinpoint the behavior and aptitude of IWDs. Unless the physician is specifically trained in the observation and assessment of dementia symptoms, it may be common for them to overlook or mistake certain actions that should be the cause for concern.

IWDs can also actively mislead other people when it comes to their condition. For instance, LaToya's mother, who was cared for mostly by LaToya and her father, would actively avoid having people come over to the house in the later stages of her dementia. Likewise, as Kimberly's parents' condition worsened she noticed that they were actively avoiding leaving their home. She recalls, "They started isolating themselves. They stopped attending things that had given them that extra enthusiasm for life. Things that kept them engaged, that kept them mentally active. They began curtailing those things." Many times IWDs recognize that they are undergoing changes; while they might not understand the full scale of these fluctuations, they realize that something is different. As I observed while volunteering at Summit, IWDs often engage in preconceived exercises to hide the degree of cognitive decline they are experiencing. For instance, the very first day I was at Summit I had a thorough conversation with Peter at lunch. He was very inquisitive and I had a hard time believing that he was suffering from dementia at all. But over time I realized that this was a familiar exercise for him. When he met new people he had a series of questions he was comfortable asking and discussing. While much of his conversational skill had been lost, he stuck to the questions and topics he still remembered well. After a few conversations with him, I noted that whenever a conversation deviated from his predetermined mental list of topics he became very uncomfortable or confused. However, only someone who engaged with Peter on numerous different occasions could gain this insight. While IWDs may engage in such strategies as a survival tactic, these patterns can make it extremely difficult on outsiders to recognize their symptoms.

Given this miscellany of factors, it is common for CGs to receive less than adequate feedback from medical professionals regarding the full spectrum of interventions available to them. Since visits to the doctor can be relatively infrequent compared to informal interactions and help-seeking actions, CGs frequently discover ADCs through via these informal means. Additionally, this trend can contribute to a large number of CGs not using ADC services at all. As outlined in Chapter 1, only a sliver of IWDs utilizes ADC services. This is partially due to the uneven distribution of such services, since there are some areas with no such access. However, the knowledge aspect is also a contributor. Individuals who are forced to rely on informal networks for information about ADC because their doctors do not inform them are playing a game of chance; hopefully someone lets them know that there are more options are available, but it's not a guarantee. People with small social networks may not have this opportunity, as there are not as many individuals around them to provide this knowledge. Additionally, even those with large social networks may not have access to diverse information if this network is closed or unvaried. When medical professionals and ADC providers fail to disseminate knowledge properly, CGs suffer the consequences.

THE INTERNET AS AN INFORMAL HELP-SEEKING TOOL

Respondents frequently referenced the Internet as their preferred method of obtaining knowledge when their formal help-seeking efforts were insufficient. It is common for CGs to find useful information online that they could not even obtain from their doctors. Chelsea recalled learning through Alzheimer's blogs that it can take IWDs up to 90 seconds to process a request, which helped her interact with her mother better. Additionally, four of the 10 CGs who utilized ADCs revealed that online searches were a sizeable contributor to their discovery of Summit (Jermaine, Lisa, Russell, and Tina). Indeed, the Internet opens up otherwise-inaccessible knowledge for all types of caregivers, as long as they know what to look for. As Tina noted, “My sister actually did a web search [to find Summit]. Now, I had been doing searches for senior centers. And my sister did one for an adult day care. I had never thought to put those words together.”

However, despite the excess of knowledge available online, this is not always the easiest method to navigate. Many older adults and their families report that Internet searches can be overwhelming (Walker et al. 2017). For those who are not well versed in dementia related issues, it can be difficult to decipher legitimate sources from less reputable ones. Although some large-scale websites offer reliable information, finding localized information that is relevant to the CG may be a more difficult task. Additionally, many of the oldest old do not have the technological proficiency to resourcefully utilize online searches.

Even if online sources can link CGs with interventions targeted to them, there’s no guarantee that they will have access to those services. Jillian encountered this issue during much of her time spent looking for answers online:

> Of course you can do a ton of research on the net, and I find it comical that every cinch of research comes out of the UK. All of it. You find all of these programs and you’re like, “Yeah!” Then it’s only in the UK. Okay, well I guess if we lived in the UK we’d be set up. Which is the disheartening part because here in the U.S. there may be programs, but they’re so buried you can’t find them. How would you know? Where would you go?

OBSERVATIONS OF ECHOED HELP-SEEKING AMONG NON-INTERVIEWEES

Observations from fieldwork indicate that the same general pattern was true of other individuals who sought the services of ADCs. Attending intake meetings and spending time as a volunteer at Summit interacting directly with the CRs and their caregivers allowed for thorough observation of trends in knowledge acquisition. The most common scenarios I encountered were of CG either doing Internet searches or finding out about Summit through friends. When families would come in for observation to determine whether they thought Summit was a good fit, most had found their way there through informal networks. Although admission to Summit requires that the CR have official documentation from a physician confirming their cognitive impairment, families can schedule tours and information sessions with Summit staff prior to having this certification.

By working at the caregiver conference I was able to observe the kind of outreach that ADCs and other services conduct to target CGs specifically. At this conference, various entities such as nursing homes and home health services set up booths to bring information directly to CGs. Midway was the only organization present that included an ADC in their services. Although they were one of the sponsors of the conference and had sway over which entities were able to attend and advertise, this was not a strategy of exclusion to discourage CGs from using other ADC services; on the contrary, Midway is the only ADC provider in the metro area and beyond, so they were the only ones available.

I was placed at the Summit booth and tasked with answering questions from curious CGs. In my observation, only about one-third of CGs in attendance who came to the Midway booth were aware of ADC services prior to speaking with us. Through conversation with the CGs, I concluded that the majority of them had been in contact with formal health services regarding the health of their CR, but most were hearing about ADCs for the first time. For instance, I met a woman whose husband suffered from severe cognitive impairment. She mentioned that she had been to multiple doctors, all of which had only offered her medications or full institutionalization options. The medications did not seem to work as intended for him, as his symptoms persisted. She was managing her husband's care well up to that point, but the magnitude of the task was starting to wear on her. Additionally, her husband was not getting any type of social stimulation because they had become essentially homebound due to his condition. In the face of these pressures, full institutionalization seemed to be the only remaining option.

When the woman came to the Midway booth to speak with me, initially she inquired about my personal life instead of the Midway services. I told her about my research project and my volunteer activities with IWDs, and she actually inquired about whether I would be willing to go to her house and work with her husband personally, almost as a home health aide. She was desperate for someone to engage with him, and given my research she felt that I would be a good person for the job. I pivoted to inform her about ADC facilities, as I felt that her husband was a prime candidate for the services that they offer. She eagerly took the information I offered, mentioning that she would check into it immediately. I exchanged information with the woman; although I felt unqualified to provide the services she was seeking, I thought she would be a great candidate to interview for the project. However, I was unable to contact her following that day, so I will never know whether or not she chose to pursue ADCs.

Despite outreach in this context, those at the caregiving conference represented a sliver of the caregivers providing care in the nearby counties. Coupled with trends observed through other fieldwork and in interviews, it appears as though explicit outreach by Midway is not the primary draw to Summit's community utilization; informal outreach by CGs remains at the top of the list.

WHAT ABOUT THOSE WHO DO NOT END UP UTILIZING ADULT DAY CENTERS?

Among the 10 respondents who were not ADC users, only one expressed explicit knowledge of ADC services in their area, although all of them were aware of nursing home and assisted living facilities nearby. However, these CGs tended to have different systems of care in place. While they did not have significantly higher incomes or educational levels than the average of the sample, six of these CGs were voluntarily unemployed or retired at the time of care provision, as opposed to only 20% of those in the sample that used ADC services. Of the four remaining respondents, all three of them are employed by entities that allow them to have flexible work schedules, personal autonomy in their work environments, and significant vacation time; the final CG is a student.

This pattern reveals a potential reason why some resort to Echoed Help-Seeking while some do not. Those who are not using ADC services reached Stage 3 of the Three-Stage Model and are in a relatively balanced environment. For some, this is because the CG does not have to engage in paid labor and thus has more time to provide care. For others, it may be due to the fact that the CR had other forms of support beyond the individual CG to ease some of the burden.

For example, Christy is a homemaker. She has dabbled in part-time work before, but it was often out of boredom more than necessity. When she moved to Texas with her family they took her father with them, and he now lives in the family household. Since Christy does not work, she is able to care for his needs regardless of the time required or the day of the week. LaToya, Sherry, and Chelsea are all in similar occupational positions since they have more flexibility with their time and schedule.

In Kimberly and Brandi's case, they began providing care while they were still working. For both, the caregiving career brought enough burden to where they retired to accommodate their parents. In general, those who utilize ADCs do not have the occupational or household flexibility to make such a decision. These families were more likely to feature adults who were not at the stage in their lives where they could retire or quit the jobs they currently had. Although Kimberly and Brandi are very actively involved caregivers, they had reached a life stage where early retirement was feasible.

Meanwhile, those who eventually used ADCs perpetually remained in Stage 2 of the Three-Stage Model. While not necessarily overburdened, these CGs had not quite reached a point where their lives were as balanced as they would've liked. Perhaps their CRs were not being socially engaged, the CG could not provide as much care as was needed, or the household could not afford to have one adult leave the workforce. For instance, Russell, who is self-employed, stated that it is much too early in his career for him to consider retirement. Additionally, a number of the CGs who fall into this category have younger children or other dependents. Whatever the reason, these CG remained in Stage 2 of the Three-Stage Model through their initial informal help-seeking period and their formal help-seeking period; because they were not ready for full institutionalization but still needed assistance, they reverted back to their informal help-seeking practices to find a solution that would bring them into Stage 3: balance.

ECHOED HELP-SEEKING: CONCLUSIONS

The pattern of Echoed Help-Seeking suggests that there is a lack of knowledge sharing between physicians and ADCs. Physicians are not recommending ADCs to CGs, either because they are not aware of the existence of ADCs or because they do not recognize the CG as an ideal candidate for ADC interventions. This is consistent with prior findings suggesting providers and systems of care often marginalize CGs (NASEM Report 2016). Additionally, although the ADC does conduct community outreach, the majority of CGs in this sample did not discover ADCs through this process. Taken together, this indicates that 1) physicians and ADCs are not in consistent contact with one another, and 2) ADC outreach is not being effectively disseminated to the target population on a large scale.

The result is a back-and-forth pattern of help-seeking, resulting in CGs receiving interventions later than would be ideal or not at all. Many individuals see their physicians as authorities on all issues regarding the CR, and if the physician does not inform them of interventions such as ADCs, unknowledgeable CGs may not pursue the prospect themselves. CGs with small or closed informal networks may not have the social ties to learn of ADCs or similar interventions if not from a medical professional. The benefits of ADCs can be utilized much earlier in the caregiving process if physicians are aware of such services, especially since the physician is the one who gives the first official diagnosis of dementia. Additionally, while ADCs do engage in outreach, the scope of these efforts is not reaching CGs early on; only two respondents in this study initially discovered ADCs through an outreach effort. With better communication between ADCs and physicians, coupled with more targeted outreach from ADCs, CGs can receive the interventions they need much earlier in their caregiving careers.

Chapter 5: Caregiving Literacy

When a CG embarks on the caregiving career, they are usually not fully prepared for such a responsibility. While a few interview respondents had observed caregiving in their families, none of them had been primary CGs for anyone before (Chelsea became a CG for her mother and husband almost simultaneously). A common theme I observed in interviews was the "one day at a time" approach, similar to "muddling through" (Pescosolido et al. 1998) as discussed in Chapter 4. Although CGs recognize that there is a multitude of experience and skills that they do not possess, they know that they do not have time to pause their loved one's condition so they can learn how to deal with it. Even if they acquire knowledge from external sources, the acquisition of this information takes place while the caregiving career is progressing. Since "the unmet need indicated by many dementia caregivers is a lack of quality information about support strategies or services that can help ease the challenges of their care situations" (Gaugler & Kane 2015), many CGs figure out what works best for them through trial and error.

DEFINING AND CHARACTERIZING CAREGIVING LITERACY

In this chapter I will explore what I call *dementia caregiving literacy*, which I define as "the knowledge of and competence in proper care for someone with dementia; includes knowing the causes and symptoms of the disease and the best way to treat, maintain, and/or relieve the effects of this condition given the care recipient's specific needs" (from this point on referred to simply as *caregiving literacy*). Caregiving literacy not only involves learning about dementia, but also the general knowledge associated with providing for an aging adult (from here on referred to as *eldercaregiving*). One who is completely "illiterate" has no skills or knowledge necessary to care for an elderly person or someone with dementia; they are unfit for the role in every way. It is unlikely that any adult would be illiterate, as many of us are familiar with the basics of general care in some way. For instance, most would know that the CR needs to seek professional medical help if they are injured or suffering.

Although it may seem so, it is not possible for someone to become “fully” literate in dementia or eldercaregiving; i.e. given the vast trajectories of dementia symptoms and the potential for rapid fluctuations in mood, health, and care needs, no individual can be totally prepared to provide care to any given IWD. Even licensed healthcare professionals who specialize in dementia care may encounter IWDs who exhibit behaviors they had not observed before.

Additionally, the provision of care is a highly specific process that is based on the CR’s fluctuating condition as well as their life history. As discussed in chapter 1, the caregiving relationship between a CG and CR is highly dependent on the type of relationship the dyad had prior to the beginning of the caregiving career (Keady 1999). Likewise, the methods that best relieve or alleviate some of the symptoms of a CR’s condition can be greatly impacted by their previous experiences.

For example, when I interviewed Lisa I did not realize that her mother was actually in the house until halfway through our interview. When I initially entered the home, I heard the faint sound of singing coming from one of the rooms on the far side of the house. As Lisa and I were speaking in the living room, she mentioned that her mother was in her room listening to *The Sound of Music* soundtrack. Lisa revealed that it was the surefire way to ease her mother or keep her occupied. “I can put that on every night and she’d be happy. And then she’d be engaged in that and I could go for a walk or something if I needed to.” Sure enough, her mother, who by all accounts was prone to wander, stayed in her room listening to the soundtrack for the duration of our interview.

When I inquired further about this, Lisa revealed that the soundtrack has sentimental meaning for her mother. Early on in her marriage, Lisa’s father took her mother on a trip to Austria, which is where the original Broadway version of the story takes place. Furthermore, the film adaptation of the Broadway play was the first movie that Lisa's mother ever took her children to. From that point on, every time the film was shown on television the entire family would watch together.

> We got to eat dinner in the living room if this movie was on during dinnertime or something. She really loved the music, and she loved the story. So it has some deep connections to her, it still does. She listens to it and loves watching it, it's her favorite.

Even when her mother began showing symptoms of dementia, Lisa knew that *The Sound of Music* could calm her down during difficult times. "If she's in a bad place, it's one of the few movies I can put on and that'll burn her out of it fast. She can't sit there and not start singing."

It worked so well that Lisa bought the CD soundtrack and taught her mother to operate a very simple CD player. "[There is a] repeat button on there. She hasn't figured that one out yet, but I have big buttons that say 'play' and 'stop' for when she eventually gets tired of it," Lisa said with a chuckle. "She can still read. She can still follow simple instructions. She can still do it, and I don't want to try to do everything for her. It's just the memories attached to that."

Based on her mother's life history, Lisa knew strategies to help her on her caregiving journey. For Lisa, the discovery of this strategy helped her gain tremendous caregiving literacy when it came to interacting with her mother. However, someone who did not know Lisa's mother may have never unearthed this minute detail about her life. For IWDs who have difficulty with communication, they may not be capable of relaying these important facts to those caring for them. No CG, even one immensely educated and experienced in dementia care, would have discovered this effective and sentimental strategy for connecting with Lisa's mother.

Lisa's example reveals the notable specificity of providing care and obtaining greater caregiving literacy by increasing her knowledge and competence of proper and effective care for her mother. Each CR requires distinctive approaches for managing their care based on a myriad of factors. For the remainder of this chapter, I will discuss the elements of caring for elderly adults and/or those with dementia. First, I will explore how eldercaregiving and dementia care vary from other types of care. Next, I will investigate how dementia caregiving literacy is acquired and how it influences the trajectory of the caregiving career. After analyzing whether caregiving literacy influences the probability of ADC use, I will examine the role that ADCs play in furthering caregiving literacy.

Given the nature of my study's methodology and the abstract nature of the concept, caregiving literacy is not something that I can actively measure on a quantitative scale. For the sake of analysis, I measure caregiving literacy based on the CG's subjective perception of their ability to manage the CR. Based on how they spoke of the caregiving experience in interviews, I was able to identify three broad categories of self-perceived caregiving literacy among CGs:

- Level 1 – The CG feels like they are unprepared for any tasks associated with proper care provision (e.g. handling medication, arranging doctor's appointments, effectively interacting with an IWD), or is very early in their adjustment to this role
- Level 2 – The caregiving career is stable and the CG feels ready to handle some of the anticipated issues that will arise in the future, such as abrupt personality changes or sharp physical decline; however the CG still feels the need to learn more in order to become the most effective caregiver possible

- Level 3 – The CG feels like they have acquired the necessary knowledge and experience to manage the CR and handle any future issues that the caregiving career presents; even at Level 3, a CG is not "finished" learning, but is in a constant state of knowledge acquisition based on the evolving circumstances

Also, given that the acquisition of caregiving literacy is a dynamic process and that the individuals in my samples are at varying stages of their caregiving careers, I cannot accurately portray how many caregivers are in each stage. However, I can provide the experiences and characteristics of each stage and explore the progression from one to the next.

HOW DOES CAREGIVING LITERACY DIFFER FROM OTHER TYPES OF CARE?

As identified by Simpson & Acton (2013), emotion work constitutes "efforts made to enhance emotional well-being and provide emotional support in a relationship between two people." Emotion work also involves activities geared toward the enhancement of other people's emotional well-being. Hochschild (1979) initially made the designation between emotion work and emotional labor, which is emotion work conducted in a paid labor setting. Emotional labor involves providing care, but only in work settings.

Simpson & Acton identified four categories of dementia caregiving emotion work: managing feelings, weighing options, being parental, and ensuring emotional well-being. These four categories are all present in the context of providing dementia care. Managing feelings "refers to incidents in which caregivers' true feelings were inconsistent with the external expressions of feelings that they needed or wished to portray." For example, if caring for an individual who is incessantly aggravating, a CG should try not to let those feelings be known to the CR. Weighing options refers to the cognitive struggle that is involved in deciding how to respond to a CR. If a CR who suffers from dementia is constantly saying that a family member is coming to visit them, even though that individual died decades ago, should the CG confront them with reality and tell them that the individual has passed away? Or should the CG continue allowing the CR to believe a false truth? Being parental involves having to become an authority figure in the CG-CR dyad. This sometimes requires both to take on roles that are unfamiliar to them. Ensuring emotional well-being involves making sure that the CR stays cheerful, confident, optimistic, etc. In the face of certain illnesses or disorders, the CG may try to ensure that the CR does not fall into a depression.

As mentioned above, emotion work can take place in paid labor settings in the form of emotional labor. For example, many people who work in service industries are tasked with making sure that their customers are in a good mood at all times; if not, the employee must figure out a way to remedy the situation. Restaurant workers may have to take back a dish that is not to the patron’s liking, and even if the customer is rude the employee must maintain a smiling disposition. Those working in customer service often take verbal abuse from disgruntled customers, remain calm, and attempt to satisfy their issues. Individuals working in preschools or child daycares settle disagreements among the children, ensure that they are safe, and maintain their cheerfulness; whether the employee is having a bad day or not, they must engage in this emotional labor to adequately provide the services they are employed to do.

However, the context of emotional labor differs from private emotion work in a significant way. Those who engage in emotional labor may be allowed to relax this temperament when they are off the clock. Restaurant workers may have to smile throughout their entire shift, but if they are having an otherwise bad day they are allowed to sulk when their workday ends and they return home. They do not necessarily have to engage in the same constant emotion work with their families, acquaintances, or other strangers they see daily. Even those who provide care at work, such as preschool workers, are only required to maintain this mindset in the context of their jobs.

Among the types of care provided in the private sphere, both childcare and eldercare involve all four categories identified by Simpson & Acton. However, caring for children differs from eldercaregiving and dementia care in two major ways: first, dementia and eldercaregiving involve a shift in responsibilities. Additionally, childcare is a more normative life event.

Shift In Responsibilities and Role Reversal

The first major way that childcare differs from eldercaregiving is the role reversal involved. Parents and children, especially early in life, do not have an egalitarian relationship. Even in a generally harmonious relationship, parents (or parent-like figures) are still in a position of authority and influence. In general, parents provide for children in ways that they cannot provide for themselves. Food, housing, transportation, and clothing are all distributed in a top-down manner from the parent to the child. This relationship does not necessarily end when children reach adulthood; it is still relatively common for parents to provide support (money, emotional, socializing, etc.) to their grown children, especially in white families (Fingerman et al. 2011). Furthermore, parents are responsible for cultivating knowledge within their kids and socializing them. Immediate family members are the first agent of socialization for most children, and from this interaction they learn the proper norms and values of the society in which they exist. Even as adults, many people repeatedly look to their parents for advice in times of need or confusion; despite the fact that both parties involved are now adults, the closeness of the relationship and the parent's history of influence in their grown child's life resonate.

Spouses tend to enter their social relationships on much more equal terms. Even if the individuals meet at a young age, neither is in a position of power over the other. A pattern may emerge in which one partner is more influential in the relationship, but the basis for their connection is usually not one of dependency; one partner is typically not charged with providing food and shelter while also socializing the other. Since marriages tend to start out as more egalitarian arrangements, the nature of these bonds may persist for years or decades thereafter.

In-law relationships may fall somewhere in between these two. On one hand, in-laws may be very influential and hold position of prestige in the eyes of one's spouse, by extension exercising influence over the couple. One can also view the in-laws in a similar fashion. On the other hand, in-laws are often first encountered in adulthood and do not have the same care relationship their child's spouse as they do with their child. Individuals may not view the influence of their in-laws in the same way that their spouse does, potentially reducing their sway in that individual's life.

Given these different relationships, providing dementia care for any one of these categories brings about unique challenges. There is a role shift or reversal in each that mainly reflects on the "being parental" aspect of Simpson & Acton's characterization of emotion work; at the onset of the caregiving career, an individual who was not previously in a "parental" position is thrust into that role. For example, upon moving their parents from their native countries to the United States, ethnic Chinese Americans experience a shift in power dynamics from the parent to the child (Lan 2002). Indeed, a very common theme among interview respondents was that they felt like their loved ones were reverting back to being children. However, childcare is usually an expected role, whereas dementia care may not be. At Level 1 of caregiving literacy, CGs may still be adjusting to taking on the caregiving role; depending on the degree of the shift and how well the CR adjusts to it, these transitions can follow an array of trajectories ranging from relatively simple to quite difficult.

Adult children who have to care for their parents may have to take on roles in the relationship that they have never occupied. Parents may not be able to shop for themselves, pay their bills, or feed themselves. The role that the parent used to identify – the provider – has now been passed on to their child, and the parent has become the dependent. This reversal can have a tremendous emotional effect on CGs, who may be thrust into a role that they never envisioned for themselves. Katharine recalled the difficulty of seeing her mother’s changes:

> The child becomes the parent. Yes, it's a hassle doing that and having the responsibilities that I have, but I also hate seeing my mom deteriorate. That's really hard. Really hard. I've got to tell you, there's no common...it's nothing they teach you. It's hard, really hard.

Christy also spoke on the childlike aspects of her father’s condition:

> It’s kind of funny, he kind of reverts. It’s almost like taking care of a child really. They act like a child sometimes. But he likes to see little kids, it brightens his day. He sees little kids playing in the neighborhood and he likes that.

Christy’s father actually sat with us in their back yard as I conducted the interview. He certainly did have childlike qualities in the way that he now interacted with his daughter. Although Christy characterized the situation as “funny,” it was clear that she was wistful about her father’s deteriorating state.

She also detailed the daily routine she goes through with her father, whose condition is one of near-universal dependence:

> I take care of his food, his care, his medicines. I take him to the doctor, I have to help him at this point with the bathroom. He doesn’t even remember the steps so he has to read a list on the wall. “Pull down pants, pull down underwear.” He wears Depends because he has accidents. And then, ‘”Is it time to flush yet?” “No, not yet.”

She also has to handle or assist in all of her father's hygiene needs beyond using the bathroom.

> Generally when it's time to shower I put on my bathing suit and get in there with him. I have a shower chair. That's what I figured out, before he moved in with us and I was living apart from him, I ordered a tub mat and a shower chair when we were over there visiting. But he was still afraid to the point that he wasn't really doing it because he was afraid that he was going to fall. He thought it was too much to handle to hold the soap and the shower thing. I think he enjoys getting his back rubbed, scratched in the shower.

She recounted the previous story with a laugh. Christy also has to make sure that he is sleeping properly: "Now I have to check him every night, he's always losing his blankets. I don't know why. He gets all wrapped up and wakes up cold." In Christy's case, her father's dementia has caused him to revert to a nearly infantile state, which is an extreme role reversal for Christy to have to cope with.

Chelsea spoke about the difficulties she had communicating with her mother at times. Her dementia had sapped much of her vocabulary, so she was limited in the words she could recall to describe how she was feeling. At times, Chelsea felt like she was communicating with a young child who could not verbalize exactly what was wrong, even though it was clear there was a problem.

> I have to decipher, she might not always verbalize what she's thinking or feeling. [People with dementia] may not identify pain, they might not have the words or make the connection. That's why she says "ouch" all the time, because it's easier. She used to say "junk." Her junk means her clothes, her glasses, everything.

Chelsea attributed this to her mother's declining cognitive ability. "It's an easy, lazy way to express things so she doesn't have to think. It's kind of like a lazy brain, but it's a way she can express herself without having to think too much. That's all she can handle, so it's up to me to figure out what it means." While Chelsea's mother had been the care provider early in their relationship, it was now Chelsea's job to decipher her mother's care needs.

While the spousal caregiving dynamic does not necessarily involve a complete reversal, it definitely entails a shift in the previous script of interaction. Tina and her husband were an active couple for their entire marriage. They enjoyed hiking, camping, and anything else outdoors. Although they did many of these activities together, they were each also very independent. Tina left the home at a young age to make her way in the world, and she never lost her independent nature.

> I never went to college, I came from a very poor family. I was the middle child so I had to be independent. So I moved away from home before I ever got married. And I sort of made my way. I didn't learn to drive until I was going to move. I went to a driver's school on Monday, got my license on Friday and left on Saturday. In fact, the driving instructor took me to the car lot and I bought a car, went back to my apartment, packed my bags and left.

As a young woman in the 1950s American South, she broke numerous gender roles in the sternly independent way she approached life. She and her husband maintained this mindset even in marriage, so it was troubling to Tina when she had to begin performing routine acts for him. "He has a lot of trouble with anything that requires more than two steps. Showering, one of the biggest problems. Getting dressed. That kind of stuff. Taking the garbage from there to the garage," she says as she chuckles and gestures toward the trashcan in the kitchen. She had always valued her husband's intellect and his individuality that matched hers, but now those are gone. "Yes, from a very young age I had been very independent, and that's why I admire him…this is what's so ironic. I admired his brain. He's very, very intelligent, and I really thrived on being challenged like that.

Although in-law relationships can be complicated, Susan and her husband’s mother had a fantastic relationship for years prior to her dementia symptoms. Randy’s mother had fulfilled a parent-like role in her life for years, and the both of them took on the caregiving career when the need arose. Susan was very active in the delivery of care and has an active role in Randy’s mother’s everyday life. Susan spoke about the system she established to help Randy’s mother get dressed every morning:

> As far as special care, in her room we have all of her drawers labeled with where her clothes are because she can't remember. She'll open and close, open and close. That's just part of her OCD thing. For the week, we've got a clothes stacker, so I'll get all of her clothes together and put them in there so she can just go in there and grab a set of clothes, so all she really has to do is pick out a pair of socks that she wants for the day.

Susan’s relationship with her mother-in-law had shifted from egalitarian to the point where Susan was manually choosing which clothes Randy’s mother would wear each day. Her condition had declined to the point that the number of choices she was capable of making were very few. “We try to let her have some choices. But for her to go in there and decide what she's supposed to get dressed in, it could take hours for her to even make that sort of a decision.”

While childcare provision shares many traits with dementia and eldercaregiving, the considerable shift in responsibilities highlights a major difference. Young children are hardly ever the main providers for their parents and households, so it is not unusual for their parents to provide support to them throughout life. However, when those relationships are reversed and the historically elevated individual is relegated to being the recipient of care, it can lead to unexpected changes in the dyadic bond.

Normative vs. Non-Normative

The other fundamental way that childcare differs from dementia and eldercare is the relationship between normative and non-normative life events. This parallels the concept of *expectedness* as discussed in Chapter 1 regarding major life events as stressors. In most cases parents are somewhat prepared when children arrive. Beyond the nine-month waiting period between conception and birth, many parents actively try to have children and are thrilled when they are born. In the case of adoption, parents explicitly seek out institutions that will allow them to become parents. Childcare is a very normative life event, since the vast majority of Americans eventually have kids at some point in their lives.

However, dementia caregiving is a much more rare event. As evidenced in the NHATS data from Chapter 1, the majority of adults in the United States are not dementia caregivers; on the other hand, the 2013 Gallup poll on Americans' desirability of children revealed that over 90% of respondents either have children or are planning to have them in the future. Due to the stark difference in normativity of these events, they are perceived and approached differently. Many CGs in the sample noted that they never expected to become caregivers or that they were not even supposed to be providing care at this stage in their lives. Through my observations and interview data, I suggest that the non-normativity of eldercaregiving as opposed to childcaregiving can lead to very different outcomes in their provision.

One way that childcaregiving is a more normative is that even though not everyone has children (and even those who will have them in the future don't have them yet), most people beyond late adolescence have some idea of how to care for a child and what responsibilities are associated with such a task. Due to the sheer prevalence of children in families, many of us are exposed to children from a young age. When we are encounter very young children they are often in safe and protected settings, such as childproofed bedrooms or in the comfort of their parents' arms. In school, although we are usually in classes with kids our own age, the larger school setting features children of all grades. Mass media also give us consistent images of children, with entire channels dedicated to young people featuring shows and commercials targeted to them; books and magazines do the same. End-of-year lists of highest grossing films often feature a number of children's movies, and a quick browse of Netflix categories will reveal a number of kid-friendly options.

Given these factors, most people are very familiar with the trajectory of childhood and the general path people take into adolescence and adulthood. Even adults who are childless know that babies need their diapers changed and a particular type of baby food; although children may begin walking and speaking at slightly different ages, the most people probably know that there is a problem if a child is not doing one or both of these things by five or six years old. While there are no set deadlines on other life events, we have culturally defined stages of life at which certain events tend to take place: begin dating in the early teens, leave home and gain independence in the late teens. These occasions are even symbiotically, and perhaps latently, shaped by our educational system. We may encourage young adolescents to begin dating by hosting dances at their schools, and by making the high school diploma a de facto rite of passage to adulthood we encourage people to become independent in their late teens. Even if we are not personally experiencing those circumstances at the moment, we know these things because they are such mainstays in American culture.

The result is that we tend to be very comfortable with childcare and the trajectory of childhood. It is expected and normative. However, the process of aging, and especially of developing dementia, are much less normative. First of all, the 5.4 million Americans living with dementia pales in comparison to the number of children and adolescents in the United States. This fact alone makes dementia a less accessible process than childcare. Additionally, in all of the ways that childcare and the path of childhood is a public event, the trajectory of dementia is hidden.

The maturation process of a young child is fairly predictable, but dementia is anything but. Often, doctors cannot even explain or forecast where the IWD's condition will take them. Sometimes IWDs experience a slow descent into childlike behavior, and other times their temperament shifts seemingly overnight from docile to aggressive. Some cognitive impairment is coupled with physical declines, while some are not. A dementia patient may be able to recall events from 60 years ago but will not remember how to tie their shoes.

Additionally, while care for small children is often safe and secure, encountering IWDs can be a scary prospect. People suffering from dementia may speak about the dead as if they are in the room with them, even if that person passed away long ago. They may mutter to themselves as though deep in conversation despite having no audience. Those suffering from cognitive decline may bring up painful or awkward conversations at inopportune times, or they may mistake you for someone else. Additionally, I encountered many people throughout my fieldwork who, while awake and alert, seemed as if they were staring straight through me as if I were not even there, which is truly an eerie feeling.

There are no television channels dedicated to people suffering from memory loss, and no magazines or books featuring them in the checkout line racks at the grocery store. While some films may feature elderly people or those with dementia, the numbers pale in comparison to the same types of media catered to the younger demographic. We do not go to school with people who have dementia, and we don't get to see the natural progression of the disease take place before our eyes in the same way we observe first graders progress to second and third. There are nursing homes in almost every city large enough to support one, but honestly most people probably do not go there unless they have a reason to. Even if we do visit, many of the residents are shut away in their rooms or sleeping. While many children are encouraged to play outside, elderly people with dementia may be homebound or unable to function outside of the safe environment of their houses. We may interact with people suffering from dementia if they are family members or friends, but that may be the extent of it. Otherwise, we literally do not see them.

Kids are expected to progress through childhood and grow up. However, no one can be sure that their elderly acquaintances will develop cognitive impairments. It's an entirely "wait and see" process, inherently different from the inevitable feeling of childhood. All of these factors combine to make dementia a potentially scary, confusing, and mysterious disease. The non-normativity of dementia and eldercaregiving stems from this unfamiliarity and the fact that most of the CGs in the sample never expected to be in the position that they currently find themselves in. Dementia CGs may feel intense emotions when encountered with a situation they couldn't predict, largely because of their shattered ideals of how their lives were "supposed to turn out."

Jillian reflected on how she always expected her children to be close to their grandmother, only for her to develop dementia as they grew up:

> I have two young kids. They've been really good troopers, but I also feel like they've been robbed because they don't get to have a grandma. Most grandmas, you got to bake cookies with them and have fun times. Well mom was working the whole time they were small, thinking that when she retired she'd be able to spend time with them. Well she retired and then that went away.

Jillian's idea of how things were supposed to be for her kids can never be possible with her mother's condition. Additionally, she thought that she would only have to manage instrumental tasks for herself and her family, only for her mother's needs to change abruptly:

> As far as things that I normally wouldn't have done, for instance I wouldn't have managed her finances. I wouldn't have done her doctor's appointment. Those things that, well she's a grown woman, she can take care of her own stuff. Now that's what I do. I handle all of her finances.

Jillian's responsibilities don't stop there, either.

> If she needs a new jacket, a new blouse, a new pair of pants, I'm the one that takes her and tries the stuff on with her and whatnot. All of her medical stuff. We had to do power of attorney stuff, it was getting really difficult constantly saying, 'I'm calling on behalf of my mom.

Jillian's idea that her mother is a "grown woman" who normally would be able to handle these issues herself is inconsequential as her cognitive condition deteriorates.

Tina never thought that she would live out her advanced years feeling alone as long as her husband was alive. Yet, dementia has reduced him to a shell of his former self, leaving Tina feeling deserted.

> But the hardest part about living with him this long is loneliness, she reveals, before taking a long pause to gather her emotions before continuing. "He can't carry on any conversation. His social skills are deplorable. You can't really take him to a restaurant, you can't take him to a movie. [Summit] used to take them to a movie but it was the whole group of them in the morning. But I can't go anywhere with him.

After working their entire lives, Tina expected they would spend their retirement doing the outdoor activities they loved, such as birding and stargazing. Her husband's condition has robbed them of those opportunities; if Tina wants to engage in them, she must do it alone.

Jamie had to drastically adjust her life in order to provide care for her parents, who still insist on living alone despite their health conditions. Jamie is tasked with constant monitoring from afar, and often has to drive to assist them for even minute issues. Since they live in assisted living and not nursing homes, Jamie's parents do not receive institutional assistance with all of their care needs. She wistfully spoke of the time she knew had passed her by:

> It's not where you think you'll wind up when you're in your 20s and 30s, even 40s and 50s. But watching older people age gives you that overwhelming feeling too. Like yeah, this is what old age looks like. I feel overwhelmed with it a lot, because it's not time limited. This is how life is now. This is, for the foreseeable future, how this is. And I kind of just take a deep breath and say, "This is what you do."

The care needs are exacerbated by the personality changes her parents have undergone over the years due to dementia:

> My mom is a sweet lady but she's not he mother that I remember. The one who was extremely competent and could carry on a conversation, cook dinner, and give you directions at the same time. Now she couldn't even bring you mayonnaise and mustard in the same trip. Seriously! Watching that decline in ability…she can't even walk and carry on a conversation at this point. If she has to talk she stops.

It took Roberto a long time to come to terms with the idea that his wife's cognitive changes were permanent. Previously socially active, Roberto's wife's condition largely confined them to their home as is progressed. Her condition was characterized by extreme fluctuations in mood, combined with physical deterioration. Early on, Roberto attempted to preserve his wife's condition and help her retain as much as she could, but he eventually gave up on this endeavor: “It took me five years to get to the point where I could live in the moment. I have zero level of expectation. If she did something, fine. If she didn't, so what?” He admitted that his children still have a long way to go to reach the point he has.

> I don't think they're at the point that I'm at. The point I'm at is that the person I loved and married and lived with is gone. She could be dead and it wouldn't be any different. They're still at the point where they remember Mom, and they haven't accepted the fact that Mom is gone. Never to return.”

He recalled a recent example.

> We went, the kids and I, we visit her the day before Christmas. We're walking out of the facility and my son said, “That was tough.” And I said, “No, it wasn't.” He asked what I meant and I said, “When you accept the fact that the person you knew and loved is gone, it's not hard.”

Jermaine and Sherry, who had lived many places throughout their adult lives, had planned to settle down in old age and life out their remaining years in the south. However, health ailments for both of them stand in the way. Sherry’s condition does not allow her to travel much at all, and though Jermaine is more active he also has minor physical issues. Jermaine spoke about the restrictive nature of their situation:

> I'll say this about caregiving: the problem is finding time to do what you want to do. It's difficult, not impossible. The goals that you had when you were saving for your retirement...we were going to move down to the Texas coast, go down to New Orleans, spend a weekend here and there. We can't do that, she's not up to it. She can't really see. That changes. But outside of that, instead of being out and about you're homebound. Caregiving is homebound, at least from my point of view. You either like it or you don't. Those who can afford it, and have the desire to do so, would probably try to go to a nursing home. But we're not going to do that unless we absolutely have to.

One exception to the concepts of normativity discussed above may be situations in which parents have to care for terminally ill children. Research by Jones (2012) explored trends in family care for children who have cancer. Children make up 1% of cancer patients, so having a child with this disease is quite a non-normative event. While these parents may have been fully prepared to have and care for children, they were likely not prepared to provide the *type* of care that terminal illnesses require. In general, the parents of cancer-stricken children were able to adjust and cope with their children's condition, but a significant majority of them also developed post-traumatic stress symptoms. The shift from "normal" childcare to caring for a child with cancer was disruptive not only for their own identities, but for the entire family structure. The early stages of cancer are met with uncertainty, and even further into the treatment process the family members can experience anger, fear, anxiety, confusion, and shock.

These events disrupt the equilibrium of the family, potentially causing financial distress, marital strain, and social or behavioral problems for other children in the family. Since there is no preparation for the role, caring for children with cancer can be similar to dementia caregiving in the adjustment period required. Just as most adults are not completely prepared to handle dementia care when the need arises, many parents of terminally ill children experience the same thing. Indeed, caregiving parents tend to have poorer self-rated health and more chronic health conditions than caregiving adult children (Zehner Ourada & Walker 2014), suggesting that the caregiving career for terminally ill children may involve even greater negative effects than caring for parents.

An element of this trend can also be seen in the gendered aspect of dementia caregiving. Many of the responsibilities involved in care provision are incongruent with traditionally masculine roles and norms. Once could argue that traditionally masculine roles and norms would be more strongly internalized among the oldest men in society since they grew up prior to shifts in gender roles that saw large numbers of women in the work force and men becoming more involved in family care. Research by Mills et al. (2009) indicates that being a spousal caregiver for an individual with Alzheimer's is "associated with increased risk for cardiovascular illness, particularly in males." Once again, it must be noted that on average spousal CGs are the oldest of all CGs in the United States. The men in this sample who were caring for spouses with moderate-to-severe dementia symptoms spent significantly more time awake than female caregivers in the same position; they slept approximately 54 fewer minutes per night. Findings suggested that male CGs in this situation had more disturbed sleep patterns and stayed up later providing care, perhaps because they were not as acclimated to the responsibilities associated with care provision as female CGs were. Furthermore, male CGs of spouses with severe dementia were awake 40 minutes more than CGs of spouses with mild dementia, signifying that greater care need may lead to a lengthier adjustment period.

HOW IS CAREGIVING LITERACY ACQUIRED?

Initially, many caregivers take a "one day at a time" approach to caregiving. When at Level 1 and just starting their caregiving careers, it is common for CGs to be unsure of where they should even start. For some, this approach is enough make them feel that they are sufficiently in control of their caregiving careers because they recognize that it is highly context dependent. For instance, while Russell acknowledged that seeking outside information was helpful for many people, he feels that the best way to become an effective caregiver for his mother was to jump in headfirst and learn on the job:

> Yeah, that's pretty much it, you learn as you go. Nothing can prepare you for it. It takes patience and being creative. That's why people say, "Caregivers, experienced with dementia and Alzheimer's." From my point of view, you don't need experience. You just need a few weeks and you'll figure it out. You'll figure out what do to, what works and what doesn't work. Every patient is different, I'm sure.

Sherry echoed this statement, “It’s mostly been trial and error. I think every situation is probably different.”

Of those who recognized that they learned aspects of caregiving literacy from outside sources, some referenced their previous job experience. Kimberly, Brandi, Chelsea, Jamie, Diana, Randy, Jermaine, Sherry, and LaToya referenced some aspect of their occupations that helped them comprehend the facets of dementia, navigating medical institutions, or other responsibilities associated with caregiving. For instance, Sherry acknowledged that her experience as a preschool director helped her do a better job of communicating with individuals on a personal level.

Her husband Jermaine had a unique perspective. He first mentioned his former job:

> I think I always knew the skills needed to be a caregiver because of my career. I employed social workers. I employed MSWs and was wise enough to listen to them when they were discussing what to do about things. I think I picked up a lot on the job that I was able to translate to this.

Then, he recalled a lengthy story about how his family history helped him to empathize with people who were experiencing different circumstances than he was: “The other thing that I'm sure helped me was my dad. He was a minister, so he in effect was in the caregiving business. To do that you have to learn empathy. You learn about racism because you see it in your own father's job as a minister.” Recalling a specific instance, he said:

> The most striking example of that is when we lived in a little town in the Midwest. My dad had a Disciples of Christ church. He was paid a visit by a black family. This was back in '55, maybe '54. They wanted to come to the church, and my dad said, “Sure, please.” They wouldn't sit downstairs, which always bothered him. They always sat in the balcony. I remember he came home one day in a rage.

> They had sent members of the board of elders and deacons who weren't happy with that. Knowing my dad, he stood up and said, “They'll be in church Sunday or I won't be in church Sunday, or any Sunday after that.”

For Jermaine, seeing his father relate to and empathize with people of a different race helped him understand the importance of building bridges, finding common ground, and understanding his CR.

> That quieted them down. People like to be comfortable where they're at. I think we were the first church in the town to welcome black folks. I grew up with that. So translating that into this, she's my wife and we've always been close. We always discussed issues, personal issues. Her easier than me.

A few CGs had found great help in support groups. Christy spoke of a woman she met who went to great lengths to disseminate caregiving knowledge:

> She runs these support groups every week at various facilities and offers a ton of resources. She’s really good at networking with different people and getting guest speakers. Companies that provide care, nurses, [and] experts in the field of caregiving for seniors, like vet

Chelsea also spoke on how support groups give her the opportunity to gain insight from others going through similar situations:

> We get that from the support group, where we can talk about things. Not all support groups allow interaction between the caregivers, but I need and want that interaction. I want to know what you know that can help me, and I’d be happy to share what I know to help you.

For CGs who have access to individuals who have already provided similar types of care, whether through support groups or other means, the advice and strategies they receive are among the most valuable contributors to caregiving literacy. Network inequality refers to “the uneven distribution of who we are connected with and the resources (material, social, and emotional) these connections provide” (Abramson 2016).

Although they are unevenly distributed in society, having access to a network of people who have experienced caregiving gives the CG an immediate advantage, as long as these individuals are willing to share information. Many CGs in the sample noted that some of the best guidance they had received came from individuals they knew through informal networks.

Chelsea considered the information she was able to gather from other CGs the most valuable caregiving commodity available: “Tips from family caregivers, they’re the best resource. ‘This is what I did, this happened to me, and this is how we handled that. I went to this doctor, that medication has that, this didn’t work,’ all that stuff.” April credited her doctor with pointing her in the direction of great resources, but also credited informal interactions with individuals who have provided care before. “Well, I learned a lot about caregiving from other folks who have been through it, that helps a lot. I also read a lot. And finally the doctor. She's got the best doctor, primary physician.”

Formal caregiving education programs are also tremendously beneficial. Research by Zarit et al. (2011) on caregiving educational intervention projects outlines the benefit of such programs. This study tested the effectiveness of psychoeducational interventions designed to “facilitate transition to the caregiver role following diagnosis of Alzheimer’s disease in a relative.” Post-test and follow up, the CGs in the experimental group:

- were more confident in dealing with caregiving situations,
- perceived themselves to be better prepared to provide care and more efficacious in their caregiving role,
- were better able to plan for the future care needs of their relative,
- had better knowledge of available services, and
- made more frequent use of the coping strategies of problem solving and reframing

These findings illustrate how proactive interventions early on in the caregiving career can foster caregiver adaptation to the challenges they will likely encounter in the future. These characteristics can also be seen as a benchmark for caregiving competency, as the CG is on their way to acquiring a holistic understanding of the multifaceted care process.

External forces such as these foster the skills numerous CGs learned to get them from Level 1 to Level 2 or 3. Many cited the use of community programs and seminars geared toward educating the population on issues associated with aging. Following Kimberly's retirement, she sought out classes to help her understand caring for older adults. "When I took retirement I got hooked up with a series of classes that were community-based, through the local Methodist church on caring for the elderly. That was the first series that I did. And I'd look for other opportunities for classes that were maybe once a month or whatever." Having been at Level 1 through the early stages of her parents' illnesses, Kimberly sought to advance her knowledge so she could be more competent in assisting them.

> I would try to learn from every one that I went to. What's good, what's helpful? I started another series on the different stages of dementia. It's called GEMS. But I would look for classes and opportunities to learn about helpful strategies. I read books…. Just being proactive in terms of what would help. What can I continue to learn so that it hopefully makes this process better?

While Midway operates two ADCs, much of their outreach and resource allocation goes to outreach for caregiver education. Midway was the main sponsor of the caregiving conference I attended, and they feature ongoing classes throughout the metro area on caregiving strategies. Jillian and Ken both spoke about how they used books, pamphlets, and online resources, which had given them access to great tips and strategies for providing their mother's care. However, they were both huge proponents of the resources provided by Midway.

Jillian spoke about how information she gathered from Midway helped her understand her mother's condition more comprehensively:

> We just needed to know what stage she was in, because by that time my brother and I had the realization that we really needed to learn what this was all about. We started reading and learning about the stages. But it wasn't until she was diagnosed with Alzheimer's and we really started reading up on it and attending these Midway caregiver classes that we realized in actuality she was probably going down in her mid-40s.

In her opinion, Midway helped consolidate knowledge that was otherwise difficult to obtain.

> The resources, you don't know about them. You don't hear about them or know about them. Midway has been a godsend because we get all of our information through them. But even when she was at the senior center [which they utilized prior to Summit], which is phenomenal by the way, I would get just little bits and pieces.

Ken felt similarly:

> Luckily we had resources. Midway has been a godsend, not only because they're taking care of Mom, but because they've given me resources, training, and help to make sure I didn't flounder or fall under. If I need to go back to a class I can, I'll just take it over again. Any type of service you can do, helping people to cope, letting them know that they can't become static, don't become complacent. Yes it's hard, but it can be done. Get help.

While most caregivers sought some kind of knowledge to advance past Level 1, they acknowledged that not all of these tactics were fruitful. As illustrated in Chapter 4, some informal help seeking strategies such as online searches can be overwhelming for the CG. Additionally, the knowledge disseminated by community institutions, books, and other caregivers are not a one-size-fits-all proposition. The highly specific nature of dementia care leaves the possibility that no particular strategy will work in a certain individual's caregiving career; not all information is useful or will work all the time. Chelsea touched on this concept as it relates to her mother:

> So even though everyone says, "Give her a project!" sometimes projects just stress her. Like if I ask her to help with dinner sometimes we just get in each other's way. A lot of times if she asks if I need help and I say no, she'll say, "Oh, thank God." And I know that she needs rest, so I'm not going to make her stand there.

Chelsea recognized that some of the strategies that worked with other CRs would not work with her mother and husband. Even within her particular caregiving career, some strategies that worked previously lose effectiveness:

> We've got it. And it's a learning experience, it's never-ending. What worked yesterday may not work that night, or this morning. And sometimes it'll work for two weeks, and then something changes and you've got to go with the flow. For my husband…well, with her she needs stimulation, but it has to be the right stimulation. I've tried puzzles, sorting photographs, looking through magazines, reading a book. No, no, no.

Interestingly, through trial and error Chelsea discovered that her mother absolutely loved live music.

> My sister took her to a concert with Third Day, the contemporary Christian music. That's what she was into, very religious. So my sister took her and my mother loved it. So when she was here, and seeing how she loved the music, the Christian contemporary music, which I learned to like, I was looking for something for mom to do. What could I do to get her out of the house that she would enjoy? Not that I would enjoy, but something that she would enjoy.

Using this clue, Chelsea sought other similar opportunities.

> I came across a place having a concert. I checked it out, and lo and behold there was a guy there who I heard on the radio. I said, "Look Mom, this is the same

> guy." So I looked him up on YouTube and asked if she would be interested in seeing him since he'd be here in concert. She jumped, literally jumped. "Yes, yes!" Oh gosh, she lost it.

Her mother ended up loving the experience, which initiated years of attending live music venues with her mother.

> I took her, and she stands up, laughs, dances. And I said, "Oh my gosh, I've just seen the light. I haven't seen this side of Mom." The light was back! And she always says, "My legs are so weak [when she is at home]." Well they weren't too weak to jump up and down! So obviously there's a mental and emotional connection, something is going on here. It can't be just physical, it's in her head.

By exploring her mother's passion for live music, Chelsea discovered that mariachi bands were her favorite. Similar to Lisa's mother, the musical connection was a catalyst in their caregiving careers. Chelsea had discovered a critical method for engaging her mother.

> She lives for mariachis. I'm mariachi'd out to he honest with you. The party doesn't start until my mother gets to them. We go on Friday nights, and she dances. It's a restaurant, she dances to the mariachis in the middle of the restaurant. Does she care? No. Although they did tell her to only dance on one side because she was getting in the way of the waiters.

HOW DOES CAREGIVING LITERACY INFLUENCE THE TRAJECTORY OF THE CAREGIVING CAREER?

Those whose interviews suggested they were at Level 2 or 3 of caregiving literacy noted that having these skills positively impacted their caregiving careers. One major aspect of this trend was the acquisition of better coping mechanisms. Carr & Umberson (2013) outlined the concept of coping and how it is influenced by social support and mastery. Coping involves "cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person." In the caregiving context, coping is the ability of an individual to handle the responsibilities and impact of providing care; these responsibilities and impacts may be mental, physical, social, occupational, etc.

Involved in coping are resources, strategies, and style. Coping resources are "the personal and social attributes individuals draw upon when dealing with stress." May of these resources, such as books, classes, and other caregivers, were discussed in the above section. Additionally, coping resources can include personal characteristics such as dedication or perseverance, which would conceivably allow the CG to better cope with the stressors at hand.

Coping strategies refer to "the changes people make to their behaviors, thoughts, or emotions in response to the stressors they encounter." Coping strategies can be either problem-focused or emotion-focused. Problem-focused coping involves "Trying to alter the situation that is causing the stressor or preventing the stressor from recurring." An example of problem-focused coping in the caregiving context would be if a CG hired a housekeeper to clean up after a CR who can no longer clean for themselves. The issue at hand is a messy house, and the CG takes action to remedy the problem. Emotion-focused coping occurs when "one alters their reactions to and feeling regarding the stressor, such as finding the humor in the situation." For example, if the hypothetical CG whose CR could not clean up after themselves chose not to hire a housekeeper and instead decided to simply not be as bothered by clutter as they used to be, they would be taking an emotion-focused approach to the problem. The CG is altering the way they view the stressor in an attempt to remedy its negative effects on their mindset. In general, problem-focused coping is the more effective way to avert stress. Emotion-focused coping can be effective in certain contexts, typically when the issue causing stress cannot be avoided.

Coping style is “one’s general orientation and preferences for addressing problems, such as confronting versus denying.” One’s coping style tends to be measured on a spectrum of activity vs. passivity. An active coping style may involve vigorously pursuing solutions or mediators for whatever stressor is present, while an individual with a passive coping style may attempt to endure the stressor without seeking outside assistance.

CGs in my sample consistently noted how acquiring caregiving literacy helped them develop better and more effective coping strategies. Multiple CGs mentioned that early on in their caregiving careers they overloaded themselves and tried to do too much. This was common at Level 1 of caregiving literacy, prior to adopting more balanced self-care strategies. CGs who were at Level 2 or 3 often commented on the transition from overburdening themselves to taking a step back. Brandi hardly took vacations when her father first moved into their household. However, over time she realized that this was not a healthy practice:

> You need a break from that constant caretaking responsibility every day. So sometimes during the day I’ll take a break, like this is a very nice break. Or I’ll go with my husband to do some work that he might have going on at his business. It gets me out. But I’m talking a vacation, like when you have nothing to get up for or put someone to bed. Or make something to eat, or anything.

Chelsea has a similar outlook:

> I’m very careful now where I give. If my to-do list only gets longer, and probably yours too, I cross one thing off and add three. Of if one task involves five different things and I can only get two of those done today. Everyone has been fed and watered, everyone is safe, no one is crying or dying or in danger. Then this pile of things can wait until tomorrow. The laundry is still going to be there tomorrow. I like a clean and spotless house, but I didn’t get it today.

She is learning to adjust through emotion-focused coping as well.

> I'm learning to live with dust. I'd rather sweep, which takes me two hours, but I've accepted those Swiffer things. They don't clean as well as I'd like, but in a pinch that's what I'll do because that's all I have time for. I'm learning to live with that. You adjust. It's about being realistic. I'm not about punishing myself. What for? Why? Just because I can't do grandiose things every single day, it's okay. I do what I can, and I know that I'm helping two people.

Christy is also working on emotion-focused coping strategies:

> We watched a movie about a woman, she was older than me. But she collected dolls and used to go out dancing and stuff. But eventually she got herself so worn down that she ended up getting sickly and predeceasing the person she was caring for. So now who is going to take care of that person? They don't take care of their own health.

This film contributed to Christy's shift in thinking, and she is now more comfortable taking time for herself even though her father requires extensive care. "It helped me to not feel guilty. I like to go and do jazzercise in the morning. He would normally sleep late anyway, but it just feels better. That's what I need to do to get exercise every day and socialize every day with the ladies." Christy also took local caregiving classes that helped her realize she didn't have to wear herself down providing care.

> I went to this senior center that offered a course that was called Powerful Tools for Caregivers. So I went there and took their course, it was maybe five sessions or something. They give you coping skills and things you can do to help. I learned how important it is to…well at first you feel like you've got to do everything for them. You learn how important it is to take care of yourself.

Through friends, family, and reading up on the course of dementia, Ken realized that he was putting unnecessary pressure on himself by dwelling on the past. As he learned more about the trajectory of dementia, he came to terms with its irreversible nature. This understanding helped him move beyond the helpless feeling of Level 1 into a more knowledgeable phase.

> It's so easy to live in the past…or worry about the future. I have to come back to the present. I have to keep reminding myself that I have to deal with now. How is she now? What is she doing now? It's just that. Also, coping mechanisms. People keep reminding me, "Take care of yourself. You've got to take care of yourself." So I'm working on that now. I go to yoga, try to make sure I get a little walk in.

He also learned that pets can be valuable additions to the caregiving career:

> I have a dog. I highly recommend it to any caretakers. Animals are actually pretty cool. She's my co-caretaker. My mother speaks through her, I've been decoding that as well. If the dog is scared, she's scared. Whenever she attributes an action to the dog I know it's my cue to listen, because she's trying to tell me something.

Social support includes "the instrumental, emotional, and informal assistance that one draws from others." This concept was introduced in Chapter 1. Through the action of acquiring caregiving literacy, CGs can become a part of groups or networks that enhance their level of social support. This acquisition can also help them discover where they can look for more support, a skill they may not have developed otherwise. For example, in the previous section Christi and Chelsea spoke about their appreciation for support groups and the help they provide. Additionally, Ken and Jillian are huge advocates of Midway courses and the knowledge that they were able to gain from such institutions.

Mastery is an individual's belief that stressful circumstances can be controlled and managed. This concept was also explored in Chapter 1. Acquiring more knowledge and ascending the levels of caregiving literacy can conceivably help a CG obtain a greater sense of mastery. Groups that have historically had less social and economic power (women, ethnic minorities, those with low levels of education) tend perceive themselves as less in control of their life circumstances, so achieving a high level of mastery may be especially beneficial to these groups.

In the previous section, Kimberly spoke of the classes she sought out after her retirement. Her parents had refused to move into an assisted living facility or nursing home, presenting unique problems for Kimberly and her family. As long as they insisted on staying in their home, Kimberly's could not intervene as much as she would have liked; she could not monitor her parents 24/7 and they were potentially hiding some of their difficulties from her. However, some of the strategies Kimberly learned in her classes helped her gain a feeling of mastery over the situation. She felt that with her new understanding of aging and dementia, she could implement more effective tactics to assist her parents. For instance, due to confusion her parents were unable to properly take their medications. Kimberly would often write down instructions, but they were unable to adequately follow them. However, after obtaining a better understanding of dementia and how her parents perceived their environment, Kimberly decided to stop writing instructions and pursued a different method. "We found this little alarm clock that became a lifesaver. We bought her a little alarm clock that spoke to her, and you could set it for morning, afternoon, and night meds." Her newfound comprehension of dementia helped Kimberly recognize that while her parents may never recover the ability to properly follow written instructions, their ability to follow verbal instructions may still exist.

DOES CAREGIVING LITERACY INFLUENCE THE PROBABILITY OF ADULT DAY CENTER USE?

On the journey of acquiring caregiving literacy, does this knowledge acquisition make is any more likely that the CG will pursue ADC services? Data from interviews suggests that being more caregiver literate helps CGs anticipate problems or recognize issues, which may lead them to see ADCs as a solution.

Ken recalled when he first began noticing his mother's wandering tendencies. His mother was home alone for a few hours each day, and at times felt as though she was drifting too far away from home when she was alone. Although he was monitoring it, he realized that if this trend progressed his mother would no longer be able to stay home alone. Once Ken was alerted to the existence of Summit, he knew it would be an adequate solution if her daily wandering worsened. One day, a friend alerted him: "It was getting to the point where the neighbor said, 'Yeah, she's staying to walk off on her own. She's really having problems, she needs more attention and monitoring.'" Having anticipated this problem, Ken and his sister were able to enroll their mother at Summit soon after.

After consulting other caregivers and her mother's doctors, April acknowledged that her mother's condition would progress even more quickly if she were not mentally engaged. April, who works full time, felt that her mother would not be stimulated enough if she remained at home alone every day. Luckily, Summit was able to remedy that issue.

> I never knew that there were places like that. I knew about recreation places where they would go and play bingo, but I never knew there were things like [Summit]. Like I said, I wouldn't be able to work without it. And it's beneficial for her because she's around older people.

Even if April were able to stay at home with her mother, she felt that there would not be enough variation in her activity level.

> If it was just us in the house together, no telling what it would be like for her. I think she would really go downhill. I think her dementia would set in, I really do. Getting out and socializing has really helped her. She probably wouldn't be here today if we never found Summit. It's a blessing.

April has no intention of changing her mother's routine.

> Even once I retire I want her to go. If she can still walk and get around I want her to go for four or five hours. It might not be all day, but she needs to go and socialize. I'm not going to let her sit here. Because I'm not going to sit here, I like to do stuff. I keep myself busy. And I know that if I don't make her go to Summit she would really go downhill, she'd be gone before you know it.

CGs may even recognize that ADCs are beneficial for their caregiving careers not because of what it provides to the CR, but through the element of autonomy it provides in their own lives. Jermaine and Sherry, who provide a degree of care to each other, acknowledged the benefit of Sherry attending Summit for Jermaine's health. Said Sherry: "And that gives him the opportunity to do something that he wants to do, which is walk around the lake down the street. Which he can't do because someone has to be here with me." Jermaine added:

> I get my exercise when she's at Summit, I go over to the lake. It's just an eighth of a mile away. And it's three miles around, so I can walk that in less than an hour. I get my exercise there. And if I need it my son has a gym at his house, so I can go over there and work out. So you know, I don't have any real complaints. I can dream up a few, but most people have it a lot worse than we do, to be truthful.

WHAT ROLE DO ADULT DAY CENTERS HAVE IN THE FURTHERING OF CAREGIVING LITERACY?

Throughout interviews, a common theme from ADC utilization among CGs was that it allowed them to monitor the CR in ways that might be unattainable otherwise in settings such as nursing homes or assisted living facilities. At Summit, the staff is in constant contact with CGs, especially those who bring their CR to and from the facility every day.

For example, Ken has a very good relationship with the Summit staff. Either he or his sister transport their mother every day, and they are in consistent contact with Summit employees. Ken stated:

> But as far as Summit goes, it's piece of mind, information, a good dialogue. Like yesterday, one of the workers told me, "Your mom was really agitated, way more than she's ever been." So I'm like, "Okay, that's good to know." Because I's usually indicative of a UTI. So now we're panicking because now we've got to take her in, but the communication is really good. It's helped. And they'll tell us, "We noticed that your mom didn't have her glasses on today." Just certain things, you know? Wearing too many shirts [laughs], those types of things. So it's kind of like having relief and a bunch of other little mother hens besides us all the time. I think most of it is just providing that information that you just can't seem to get anywhere else.

In a nursing home or assisted living facility, Ken may not have as much steady contact with the institution's staff; additionally, they may not monitor his mother with the same consistency that Summit does.

Those who do not have any social contact with family or formal assistance to help with caregiving knowledge report higher mental effort and are more depressed (Juratovac & Zauszniewski 2014). Furthermore, stay-at-home mothers "tend to have smaller social networks, financial dependence, and social isolation" (Frech & Damaske 2012). Stay-at-home CGs may suffer similar consequences given the nature of their role; utilizing an ADC conceivably gives the CG the opportunity to expand their social network and reduce isolation by giving them access to ADC employees as well as other CGs and CRs. Jermaine and Sherry, who takes the Summit bus to and from the facility, made note of this during our interview. After Sherry mentioned that she loves the bus service, Jermaine revealed that even though he rarely goes to Summit himself, he speaks to the staff person driving the bus each day, as well as the other members:

> The bus drivers are generally very nice...I've only been [to Summit] once or twice. I don't know any of the staff there. I talk to [the program director] on the phone every now and then, but I'm satisfied with them from what I see and hear. I make a point of talking to the people on the bus. I always kid with the people on the bus. Sherry says that too many of them just sit there with their heads down during the day.

Despite not personally visiting Summit as some other CGs do, he is still able to gather information by speaking to the staff and members when they come to he and Sherry's home each day.

CONCLUSIONS: CAREGIVING LITERACY

It bears mentioning again: no individual can ever be "fully" literate in caregiving. The term caregiving literacy describes a process of constant learning and suggests that effective care strategies and knowledge can be learned and internalized. Although there are many similarities and differences between providing care for individuals with dementia and children, a major difference is that one type of care tends to me more visible in every aspect of life. Thus, many people may have little or no caregiving literacy (relative to child care literacy) prior to being thrust into the caregiving career.

Literacy can be built and acquired through a variety of processes, and as indicated by the respondents in this sample, it can help CGs do a better job of coping, planning for the future, and interacting with the CR. ADCs are a part of this process by providing external resources and the monitoring aspect of the care environment. While it is not necessary that a CG have every bit of knowledge possible, advancing smoothly into the later stages of the caregiving career requires adept internalization of caregiving literacy.

Chapter 6: Summit and the Provision of Care

DIALOGUE WITH ABRAMSON: HOW DOES SUMMIT ACHIEVE THE GOAL OF SERVICING BOTH THE FAMILIES AND THE CARE RECIPIENTS AS CLIENTS?

Corey Abramson writes in his 2009 article, *Who Are the Clients?,* of a day care center (CADC) and its procedure toward fulfilling its goals. Abramson explores the provision of care at CADC and how well the institution is able to cater to its intended clients. Overall, ADCs aim to create an environment that is meaningful and safe to improve the quality of life for the patients, provide respite services for family caregivers, and delay permanent institutionalization

The article had four major findings:

1. The institution had a limited pool of external resources of questionable quality
2. Simply providing care to a difficult population stretched the organization to the limit; providing anything beyond that was considered unreasonable (as it would require training, personnel, and resources)
3. Focusing on respite was seen as reasonable and worthwhile; thus, the family caregivers came to supplant elders as the de facto clients of CADC
4. The goal of improving the lives of the elders and their families remained only in ideology, not practice (in the form of pamphlets, etc.)

The institution suffered from goal displacement, which meant "the major goals claimed by the organization are neglected in favor of goals associated with building or maintaining the organization." The entire organization, while originally meant to fulfill the three goals of ADCs, could not approach these expectations based on a lack of resources. CADC thus reverted to solely a respite focus, as indicated by three trends:

1. The daily programs were highly routine
2. Staff handled clients indifferently regardless of their ability level

3. The center accepted any elder into the program

As a respite focused center and not an elder focused one, the clients became the primary CGs and their families instead of the people attending CADC. In this chapter, I will explore how well Summit fulfills the three main goals of ADC services and whether it maintains member-focused clientele, while also analyzing their methods of care provision in comparison to CADC. I will draw on 18 months of fieldwork at Summit, which included volunteering at the facility and numerous conversations with staff, mostly Molly, the program director, and Maya, the activity director.

POTENTIAL BENEFITS OF ADULT DAY CENTERS

For the IWD, ADCs provide a chance to be social and to participate in staffed activities such as music and exercise programs. ADCs also commonly provide some or all of the following services: counseling, health services, personal care, therapy, and accommodation of special needs. Abramson (2009), chronicling the daily operations of an ADC through participant observation, noted that routine and uniform activities form the backbone of many day care centers. Examples include memory exercises, reminiscing, cooking, mild body movement, games (such as chair volleyball), arts and crafts, and gardening. Simply keeping the members moving throughout the day is a health benefit, as even moderate physical activity among elders is associated with a lower risk of dying; assessing members by their ability to stand for long periods or engage in mobility exercises can be used as a screening for mortality (Olaya et al. 2017). ADCs can also be a source of friendship groups for members, and increased social support can influence mental health through better self-esteem (Kim & Thomas 2017).

As improving the quality of life for the members is a goal of ADCs, activities and social engagement are at the center of the agenda. These activities, intended to engage and invigorate the members in a way that would not be possible if they were isolated at home or in less socially focused elder care institutions. Since elderly adults who feel younger tend to have more depressive symptoms, while those who feel older tend to have more depressive symptoms (Choi et al. 2014), perhaps keeping people active and socially engaged and helping them feel “less old” can improve cognitive and emotional health.

Most older adults prefer to age in place (Pruchno 2012), and ADCs give them the opportunity to do that. Full institutionalization requires that the CR relocate to the facility, but many CGs are unable to accommodate them at home due to career or other obligations. ADCs are a sort of in-between option, so CGs can work during the day while not having to worry about accommodations for their loved ones.

The caregiver benefit of these facilities has been well documented, as those who utilize ADCs show lower levels of caregiving-related stress and better psychological wellbeing (Zarit et al. 1998) and the presence of supportive staff members at a care facility is associated with lower psychological stress (Ashida et al. 2017). In an analysis of caregivers using ADCs only a few days a week, Zarit (2011) found that the total exposure to stressors and stress appraisals decreased significantly over time on days that the caregiver utilized the ADC as compared with non ADC days; according to the stress suppression model (Ensel & Lin 1991), “relief from some daily stressors may allow caregivers to manage remaining challenges more effectively, specifically showing less affective reactivity to these events.” Additionally, both wives and daughters who are caregivers and who utilize ADCs for family members have fewer depressive symptoms relative to those who do not (Kim et al. 2012).

POTENTIAL SHORTCOMINGS OF ADULT DAY CENTERS: HOW DOES SUMMIT COMPARE?

However, as discussed above, ADCs are often limited in the ways they can help the actual care recipient, often due to a lack of resources or manpower. Additionally, as noted in the above comparison of various types of care options, ADCs do require the caregiver to pay for these services. Assistance may be available through Medicare, Medicaid, veteran's benefits, and long-term health insurance, not all individuals have access to these entities.

Summit specifically accepts payments from all of the above except Medicare. Those without these payment supplement options must pay $60 per day that the CR attends. This equals roughly $15,600 per year for ADC care. Although this is cheaper than many other care options such as nursing homes, it is still a significant amount for anyone who do not have access to a payment supplement program.

Some members may not adjust well to the ADC environment. Spending significant time in a place that is perceived as stressful or dangerous can lead to feelings of fear and vulnerability, and they may withdraw from public space as a result (Lee & Waite 2018). Making new friends can be difficult, and despite effort by the staff, some members may take a while to find their social niche. The issue of cliques and exclusive friendship groups even finds its way into eldercare services. Upon arriving at such facilities, families often mention that it can be difficult for elders to make friends, be immediately included in group meals, or feel connected to others during activities (Walker et al. 2017).

At Summit, I observed various cliques but none ever seemed to be exclusionary to a degree that caused concern. One factor that helped this dynamic was that most members attend every day. Although this is not a requirement, Molly and Maya suggest that members attend as many days as possible (and for as long as possible) to build social cohesion. This dynamic can be difficult, especially considering that everyone at Summit is suffering from early memory loss. Through conversations with Maya, I learned that she felt the minimum attendance to ensure proper integration was three full days per week; anything less, and members would have a difficult time making and remembering friends.

Another issue eldercare services in general are currently dealing with is long wait lists and limited space. Due to a shortage of aides and other staff, some community nursing homes have had to refuse new admissions (Stone 2017). Summit is capped at 36 members per day in an attempt to maintain a suitable staff-member ratio. When I first began volunteering there in January 2016 there was not a waitlist for admission; however, by the end of my fieldwork in June 2017 a substantial waitlist had materialized. Summit's main requirement for admission was that a doctor diagnoses the member with early memory loss, but the discharge policy was highly subjective. One criterion used was that an individual could no longer attend when it took more than one staff member to assist them with the bathroom and other care practices. However, what if a member only required two people's assistance one a week? Every other day? In the end, it is up to the staff to determine when a person requires too much maintenance.

Additionally, the staff's understanding of when a member requires too much attention may be shaped by their attendance patterns. Summit has a bus that transports members to and from home, and many families take advantage of this service. The bus arrives at roughly 3:00 every afternoon to take members back to their homes, so after this time there are fewer people there. An individual who requires two people to assist them at 1:00 pm may be more disruptive than one who requires the same degree of help at 3:30 pm, simply because there are much fewer members present at that time.

The bus that transports members is a great mechanism for many who are nearby, but not all members and their families live within the radius of service. For instance, in my interview with Jermaine he recalled that he used to transport his wife Sherry to the parking lot of a local shopping center so they could meet up with the bus, because they were unwilling to drive all the way to Jermaine's neighborhood:

> Yes. I used to take her over to the parking lot over there at the shopping center. I couldn't do that because during the summer, when it's 100 degrees and you're sitting there waiting in a car, if they're 20 or 30 minutes late you spend all your money on air conditioning. So I phoned her and said we couldn't continue that way. They were reluctant to come out this far, but now I think they have one or two more people close by. It's easier for them to do so.

For those who live farther away and lack transportation, it may not be possible to attend Summit without some sort of intervention. As Jermaine mentioned, if there are multiple people in an area they are more willing to send the bus in that direction, placing rural residents at a disadvantage. Additionally, when dealing with elderly populations with dementia, keeping a tight schedule can be difficult. It is common for the bus to fun late on occasion, simply because members tend to move slowly. I observed the loading of the bus multiple times, and there were days when one member requires two staff members and five minutes just to get themselves situated. Coupled with cognitive decline, many members have physical ailments that hinder their movement. On days when it rains, for instance, virtually all staff and every volunteer available has to grab an umbrella and escort the members to the bus one by one. For those with canes, walkers, or wheelchairs, this is a slow process.

While healthcare is an enormous industry in the United States, workers can be surprisingly difficult to come by. Direct care jobs "are characterized by low pay and meager benefits" (Espinoza 2017), and these occupations may experience high turnover based on their structural characteristics:

- The median wage for home care workers in 2015 was barely over $10

- 67% of home care workers work only part time or part of the year, resulting in a median annual income of $13,300
- Because of low earnings, 24% of home care workers live below the federal poverty line, compared to 9% of all U.S. workers
- 51% of home care workers end up relying on public benefits such as nutrition assistance and Medicaid; many do not have any way to pay for health insurance

Along with these trends comes the potential for short-staffed ADCs and subpar training. When there is not a huge pool of candidates to choose from, care institutions sometimes have to hire anyone they can find. While Summit had a great staff in general, there were times when I observed a lack of professionalism and care for members among some staff members.

For instance, volunteers and staff often participate in the games that members play. One of these games vas basically volleyball but with an inflated balloon instead of an actual ball, so the members could not hurt themselves with it. The balloon also floated around slowly, giving the participating members more time to react to it. Audrey, a staff member, was playing the game along with a few members and me. One of the members, Carl, is a large and still relatively strong man. He remains docile for the vast majority of crafts and activities, but is hyper competitive during some games. Carl was getting a bit out of hand during the game, swinging his arms wildly when the balloon was near him. There were times when he almost struck other members, who were slow to move away from his path. Throughout this event, it seemed that Audrey never noticed or comprehended the issue at hand. She remained more focused on her own participation in the game, and allowed Carl to continue playing aggressively. I did not feel that it was my place to reprimand Carl, but I kept an eye on him to make sure that he never got too close to an unsuspecting member when he charged at the balloon and swung his arms.

Audrey and another staff member, June, were the newest workers at Summit and also on the younger end of the spectrum. They seemed to be friends, and I noticed that they were often disengaged from the members. Despite handling their minimum responsibilities, they could often be found in the office or supply room on their phones while activities were going on in the main area. I arrived at Summit one day to discover that Molly had fired both of them for precisely this reason. Molly and Maya ask for fairly consistent engagement with the members. Although it is a very laid back environment where staff and volunteers have a great amount of freedom, they do not appreciate detachment. While Audrey and June had been fulfilling some of their responsibilities, they were not emotionally engaged with the members of going above and beyond to make themselves accessible throughout the workday. As Molly told me after they were fired, "None of the members have even asked where they went."

There can also be cultural differences associated with elder care and the individuals who receive it. Research suggests that certain groups may feel more included in the day-to-day experience of being at care facilities. For instance, black caregivers who use mainstream services tend to be less satisfied with the support provided due to cultural misunderstandings (Dilworth-Anderson et al. 2002). This can lead to racial/ethnic minorities needing more support in formal service use. As with many social institutions, there can be an element of tokenism within Summit. For instance, while a few members speak Spanish, they are in the strong minority at Summit. Besides Maya, none of the staff members attempted to learn much Spanish to be able to communicate more effectively with this small number of members.

Additionally, there can be isolation among the members themselves. Those who have not been exposed to a variety of cultures may require an adjustment period when the ADC population becomes more diverse. For instance, Maya once told me a story of a member who was of German descent. When she first started, the German woman introduced herself to the rest of the group as is customary. However, one current member took exception to the German woman; many of the current member's family members had fought in World War II, and she remained intolerant of the Germans and Japanese in the decades since then.

This was tremendously stressful for the German woman, and Maya had to manage both of their emotions in an attempt to reach a balance. She spoke to the German woman multiple times convincing her that the rest of the members at Summit really did accept and appreciate her, but it was only one particular person who was having difficulty moving past old prejudices. Maya also had many conversations with the current member, persuading her to abandon her bigoted views of entire cultures and encouraging her to view people on an individual basis. Eventually the two members became great friends after having a more open-minded conversation, but initially it was a strenuous situation for all involved.

SUMMIT VS. CADC

Resources

One of Abramson's main observations was of the lack of resources associated with CADC. Like Summit, it is a non-profit facility that operates under the umbrella of a larger organization. Just about anything CADC and Summit receive is based on gifts and donations. Midway has multiple fundraising events throughout the year, and many of them are highly successful. Despite this, there is not a surplus of funds available to Summit and its employees.

For instance, at times Summit was short-staffed. Upon the dismissals of Audrey and June, it took a while for Molly and Maya to find stable replacements. Part of the problem is that while Summit pays a competitive wage for its field, this is still a relatively low wage. As Molly once told me during a conversation, “Your options are limited sometimes when you can only pay $10 an hour.” Care work of all kinds tends to be low-wage labor, and Summit is no different. Part of this problem is funding; Summit does not have the funds to hire significantly more staff or give the current staff considerable raises.

As Abramson described with CADC, the pool of employees the center drew from mostly included people with no medical experience to speak of. While some may have been certified nurse’s aides, the training required to receive this certification is relatively minimal. Additionally, many of the employees at CADC had no intention of remaining in care-related work when they left for another job; they viewed it strictly as a stepping stone into a more desirable position or industry.

Beyond pay for workers, a lack of resources includes supplies for the everyday operation of the facility. At Summit, supplies for crafts and other events were tremendously valuable. At any opportunity Maya repurposed past projects to create new ones. For instance, during the Olympics the members made their own version of the games and had a competition. As part of this, they constructed fake torches with paper flames coming out of them to represent the Olympic torch, and they were place all around the main room. Following the Olympics, Maya put the torches away instead of saving them; when the following Christmas came she reconfigured the flames to make a paper fireplace, which was placed against the wall as part of the winter decorations. Paper, cardboard, popsicle sticks, books, magazines, and anything else they could think of were used multiple times until they could no longer be used again. While this resourcefulness is useful, much of it is out of necessity due to the lack of influx of new supplies and activities that Summit receives. If it’s a slow donation season, Summit does not have the means to spend a lot on repopulating their supplies.

Due to these trends, it is indeed difficult to maintain a member-focused organization. It is far easier to simply babysit the members during the day, channeling all resources into passive and monotonous activities that keep them minimally engaged (e.g. movies). While there are certainly activities like this on the schedule, each day contained multiple opportunities for greater engagement and stimulation. This was greatly forwarded by the innovation of the staff, in the form of reusing resources and also using their own personalities to create excitement. For instance, Maya often utilized what she called "white board activities," which were word games, puzzles, etc. that she would play with the members. Hangman was a popular one with the members, but she also searched the Internet and other sources for activities that challenged them more. Finding such activities, and making them diverse enough to where they are not playing the same games over and over again, respires time and dedication from the activity director, but also an engaging enough personality to make it effective. Maya indeed made the activities more fun in the way that she presented them, serving as a lively host that encouraged participation from as many people as possible. I volunteered on multiple days where Maya shared with me that she had been up all night or woken up at 4:00 am to prepare crafts or make an activity for the members that day in order to try something new or imaginative. While the lack of resources and funds is a very real issue at Summit, these issues can be partially overcome with ingenuity and dedication from staff.

ROUTINIZED PROGRAMMING

Another observation from Abramson involved the one-size-fits-all nature of many of CADC's activities. Whatever was presented to the members catered to the lowest common denominator, rarely challenging the less afflicted members of the community. Once again, due to lack of resources and staffing, it is difficult to individualize engagement efforts. This issue was present at Summit for similar reasons, but in my observation there were efforts to counteract it.

Not including volunteers, Summit had three to five staff members present at any given time; however, there are 36 members at the facility every day. Such a ratio makes it nearly impossible to cater to the individual needs of each member. Additionally, due to the speed of their cognitive decline, individual members may lose the ability to play a certain game or engage in a particular activity over the course of weeks. Due to this, some activities, such as movies and simple crafts, were made to be all-inclusive.

Despite this, I did see an active effort behind the scenes to create a stimulating environment. The presence of volunteers helped tremendously. Volunteers could engage members one-on-one while Maya and the staff included the remaining group in games. For instance, Maya would often show movies or play music for the members, which is a passive and easily accessible tactic. During these sessions, she would often ask volunteers to participate in individualized activities with members. For instance, Jerome is a quiet member who rarely participated in group settings; he often sat in the corner alone reading, and the only time I ever saw him move around was when he went outside for cigarette breaks. However, he is an absolute whiz at dominoes. While more inclusive activities do not interest him, he can play dominoes for hours on end. Although I had never played the game before I began going to Summit, during my early days as a volunteer Maya encouraged me to pick up a set of dominoes and ask Jerome if he wanted to play. He was so inconspicuous and quiet that she actually had to point him out to me, as I could not find him among the group. However, when I asked him about dominoes his eyes lit up behind his glasses, and he rushed me off into a side room with a table. For the next hour he explained the ins and outs of dominoes to me, even letting me win a few times until I got the hang of it. When the bus arrived and it was time for him to go home, we packed up and put the set away. And Jerome, who hardly ever interacted with anyone at the center or made an effort to initiate friendships, looked at me and said, “We’ll play tomorrow,” before shuffling out of the door.

Volunteers play a critical role in Summit’s ability to individualize activities. On the average day there was at least one other unpaid worker at Summit who was simply offering their time to help out. At its maximum, I recall days when there were three or four volunteers there, including myself. Throughout the summer, all sorts of community organizations and students from local schools often spend time at Summit helping out in any way they can. Due to the influx of young people, there may be 5-10 additional volunteers available on some days to help out with various responsibilities. During this time, Maya often has regular staff and volunteers focus on administrative and planning tasks such as printing out the puzzles, coloring sheets, and activities that members will use throughout the year. She focuses the new volunteers on engaging the members since there is a surplus of help available. That way, when the outside support wavers during the school year staff and regular volunteers can focus on engagement since many of the administrative tasks are complete. Perhaps other ADCs do not have the same level of volunteer support, but this assistance is vital to Summit’s attempts and relative success at remaining focused on the quality of life of the CR.

HOW DOES SUMMIT SPECIFICALLY WORK TO IMPROVE THE LIVES OF THE MEMBERS ON AN INDIVIDUAL BASIS?

Although they are not always successful in achieving their member-centered goals to the fullest, in my observations Summit aimed for this lofty target using two broad strategies: maintaining the identity of the individual and stimulating the members physically and mentally.

Maintaining Their Sense of Identity as Much as Possible

It seems simple, and is easier said than done, but a large part of running a successful ADC is the ability to keep the members happy, encouraging cooperation and creating activities they want to pay attention to. However, a key way to reach optimal functioning is to promote the member's individuality even among the cohesive group setting. Among those using senior care facilities, elders' perception of a "good life was centered on the service providers' ability to enhance their physical, social, and psychological well-being while allowing them to maintain their sense of identity" (Minney & Ranzijn 2016). Findings from this study also suggested that older people who are cognitively intact might still benefit tremendously in senior care settings, as opposed to staying at home, despite their physical limitations.

One way Summit promotes the members' sense of identity is by encouraging, not forcing. While Molly encourages members to participate as much as possible, she is often in her office handling administrative duties. Most of the encouragement comes from Maya, the other staff members, and volunteers. During activities Maya often asks that all members, even if they are not participating, turn their chairs or join in the main area to participate. She will even go up to individual people and ask them to partake if they are slow to move. However, she has mastered the art of not making them feel obligated or forced to do anything they don't want to. This often involves compromise. Maya may invite a reluctant member to sit with the rest of the group during a game, assuring them that they do not have to participate if they don't want to. Often, they agree and end up participating anyway after they get swept up in the excitement. But those who prefer to watch are perfectly comfortable in doing so, and the other members follow Maya's lead in not pressuring them.

Another way Summit promotes the individual's identity is by focusing on what they *can* do, not what they cannot. Maya explained her rationale to me during a conversation one day. Prior to being at Summit, she worked at a nursing home. She recalled that nursing homes run on tight schedules and that in the morning, she was often tasked with helping residents get dressed. She often had only a few minutes to assist each resident, and she noticed that other workers had a tendency to dress the residents quickly and move on to the next one; due to the time crunch, they never gave the residents a chance to try to dress themselves. Maya, on the other hand, gave the residents every opportunity to dress themselves. She was often much later on her schedule than the other workers, but in her opinion it was worth it because she gave the residents the opportunity to achieve something:

> For that elderly person, putting their shirt on or tying their shoes may be the biggest thing they accomplish that day. If you're restricted to your bed most of the time or can't move very well, putting on your shirt might be a big deal for you. And I don't want to take that from them.

Similarly, she structures Summit in a way that focuses on the ability the members still have, not focusing on what they can no longer do. Even if it takes a long time, she strives to give members every opportunity to do things on their own. For instance, during crafts the members often write their names on them to distinguish one from another. Many members have difficulty writing their names and some cannot even remember how to spell them. It was a common instinct for me to focus on this inability, and for the sake of time to just write the names myself. However, after hearing Maya's rationale I slowed down and gave the members a chance. Sometimes their names were sloppily written, sometimes they were spelled incorrectly, and other times it was illegible. But the look of accomplishment on the face of someone who has not written anything in weeks is worth the wait. If illegible, I'd simply take the craft into the office and write their name in parentheses myself under the scribble. But giving each member the opportunity to accomplish something, no matter how small, keeps the focus on what they can still achieve and not their disabilities.

Closely related to this idea, Summit seeks to celebrate even the smallest accomplishments and highlight bright spots in the day. This is similar to aspects of the LOCK framework; The LOCK framework (Mills et al. 2017), currently being used across the Veteran's Health Administration, can be used "to improve quality of care and quality of life for nursing home residents and may be valuable across long-term care settings. The five tenets of the LOCK framework are:

1. Look for the bright spots
2. Observe
3. Collaborate in huddles
4. Keep it bite-sized
5. Facilitation

One aspect, *looking for bright spots*, was well implemented by Summit staff (albeit unintentionally, to my knowledge). The concept behind bright spots is as follows, from Mills et al. (2017):

> In our work using the LOCK framework in nursing homes, we instruct staff to look for local "bright spots" of positive change … asking them to focus particularly on the micro- or individual-level. If a nursing home were, for example, implementing LOCK to improve relationships between staff members and residents, they would ask staff members to conduct observations to identify instances of positive interaction. Identifying behavioral events that can serve as positive models give staff local examples that may be emulated in their own practice. This focus on where things are going well instead of where there are problems breaks two common nursing home patterns: (1) it redirects attention from deficits to strengths and (2) it engages everyone in the QI process by

> replacing abstract quality goals and metrics with concrete instances of sought-after behaviors.

By using these methods and remaining focused on the skills members still possess, Summit seeks to maintain a rich sense of self and high esteem among all members for themselves and for each other.

Those with dementia symptoms may be seen by others – family, friends, acquaintances, and even staff members – as being defined by their illness and physical limitations, diminishing their role in the social hierarchy (Bergami & Bagozzi 2000). We may even unconsciously reproduce this hierarchy by changing the way we speak to elderly people. For instance, we might use infantilizing behavior, such as elderspeak. Elderspeak is "a speech style similar to baby talk, that is used extensively by nursing home staff who care for growing numbers of persons with dementia" (Williams et al. 2003; Williams 2006). Nursing home inhabitants who suffer from dementia symptoms are more than twice as likely to display challenging behaviors (such as resistance to care) when the staff uses elderspeak (Williams et al. 2009).

Similar to focusing on ability instead of disability, Summit strives to treat all members with as much social respect as possible. Part of this strategy is referring to those to attend Summit as "members" and not "patients" or "elders." Using language that does not call attention to old age or cognitive decline is helpful in creating an engaging environment where individuals do not feel detached or that they are a burden.

Stimulating Members Mentally and Physically

Keeping members mentally and physically engaged helps to keep the focus on them, instead of simply providing respite for their CGs. While mental exercises such as white board activities have been discussed above, Summit utilizes a number of activities to help increase mental stimulation. For example, every afternoon following a snack at

2:30, Maya asks the members to recall what they have done that day. The members collectively run through the chronological timeline of their actions up until that point. Due to the dementia symptoms, many members have insufficient short-term memories, although their long-term memories remain mostly intact. Such simple exercises challenge the members to work on their short-term memories in a fairly simple way.

Maya has also created smaller subgroups of the population to prevent less afflicted members from losing the skills they have retained. One such group is a book club. Along with Sheila, another long-term and consistent volunteer, members who can still read and comprehend effectively choose a short book to read each week. Each member reads individually at their own pace. At the end of the week, Sheila and the members of the book club meet in a small activity room at Summit to discuss the book they chose. This promotes mental stimulation in two ways: First, members are encouraged to foster their reading skills, and second, they are tasked with discussing their readings in a group setting. This promotes reading for the sake of comprehension and not just seeing words on a page.

Physical health is also at the forefront of Summit's objectives. Maya always mentioned that her goal was to tire out the members enough to where they went home and slept through the entire night. Members are encouraged to go for a walk outside of the building daily if weather permits. Simple activities such as this can be important for health, as increased step counts among elderly people is associated with lower odds of future hospitalization (Langsetmo et al. 2017). Additionally, outside volunteers often come in to play music on the guitar or piano, and members are free to sing and dance along with the tunes. When transitioning between activities when tables or chairs need to be moved and rearranged, Maya encourages the members to help out the staff instead of passively watching. Even moving a chair from one side of the room to the other is more physical engagement than many members would receive in an entire day spent at home.

However, despite all of the encouragement it is still possible for members to opt out of these activities. For example, members can sometimes be found sleeping in the recliners that line the perimeter of the room. Staff never approaches members to take them up, so those who want to check out of that day's activities can simply retire to a chair and sleep. Additionally, during mentally stimulating activities members often refuse to participate. At times this is due to that individual's personality traits, but sometimes they just do not like that particular game or are having a bad day. Despite this resistance, the environment at Summit is one that encourages participation of all kinds.

Joyce and Maya: Despite All Institutional Efforts, the Impact of an Environment May Be Dependent on the Individuals Within It

One observation that was consistent throughout my fieldwork was that even in the face of tremendous institutional effort, the atmosphere and culture surrounding an ADC is a function more of the individuals who make up the institution than it is a top-down effect. The organic feelings and mood that arises from those involved at Summit are just as responsible for its engaging climate as the lofty objectives promoted by Midway.

To illustrate this example, I will describe the two individuals who I viewed as most instrumental to the environment of Summit: Joyce and Maya. Joyce is a member, although she does not suffer from the same type of early memory loss that most of the others do. Joyce's cognitive impairment is the result of a brain injury, which impacted her mental abilities. She struggles with memory at times, but she is relatively adept at many activities in comparison to the others.

Joyce is also incredibly social. She goes out of her way to speak to everyone and make sure that all who want to participate are included in activities. When I would walk into Summit every day my vision was blocked from the main room, and I would have to walk past a short wall to enter the main room. However, I could tell if it was going to be an exciting day before I even saw anyone as long as I could hear Joyce's voice when I opened the door.

Joyce often challenged me to games of cards, and she was eager to participate in any mental or physical activity that was being played among the group. Part of this is due to her condition; as stated above, she was more mentally adept than many of the other members, and perhaps did not feel the same self-stigma that others did regarding dementia. These forces may operate together and allow her to feel more comfortable engaging in the range of activities offered by Summit.

However, on days when Joyce was not there the mood was noticeably different. Games were not as lively, members were not as excited, and the mood was not as light. Although it sounds cliché, Joyce brought energy to the room. She energized other members and made them more excited to be there. When she was around, people were more likely to participate.

Even some CGs mentioned her impact in out interviews. Lisa mentioned that even though her mother sometimes forgets the names of her own children, "she remembers Joyce. She's got Joyce down." And in his interview describing his wife's time at Summit, he mentioned that she always talks about Joyce.

Although she actually works there, Maya provides a similar element to Summit. She simply knows how to work a room. She is adept at encouraging people to participate in activities, and she gets to know people on a personal level quite easily. Maya is the type of person who you feel comfortable discussing aspects of your personal life with even if you have not known her for very long. She uses self-disclosure as a way to inspire other to share tidbits of their own lives as well. In this way, she is able to create bonds between people very easily, helping the social cohesion of Summit occur more quickly. One of her greatest skills is improvisation. I recall multiple times when scheduled volunteers who were supposed to perform or conduct an activity either cancelled last minute or did not show up at all. If there was an hour marked off on the calendar for that activity, Summit now has a 60-minute vacuum with nothing planned. In these instances, Maya often just walks out into the main area and starts talking. She's a skilled storyteller, but also knows just how much to engage the members to keep their interest. Finally, as mentioned above, she often uses her own time to ensure the smooth operation of the center. She prepares crafts at home, goes to the grocery store to buy her own special snacks on holidays, and she and Molly have been known to come in on weekends to get extra work done.

However, this off-the-clock work requires extreme dedication from employees, and not all staff members are willing to make those kinds of sacrifices. It is also an unequal setup for Maya: she does off-the-clock work for the sake of Summit, but is not explicitly rewarded for it in any way.

Similar to Joyce, when Maya is not there Summit sometimes feels like a ghost town. I recall one week when Maya took a vacation, and everything seemed a bit forced. Other staff members had to take on the responsibilities that Maya has, but they did not necessarily have the same skillset that she possesses. It is possible that with adequate training and experience other people could get to the level she has achieved, but in short spurts no one can replace the energy that Maya and Joyce bring to Summit

In the context of Abramson's analysis, much of the issue he finds is structural. The clients are the CGs, not the CRs, because of the practical limitations of the organization that are extremely difficult to overcome. Issues with access to resources greatly shape the setting within which the employees and residents of CADC operate.

However, we cannot ignore the contributions that individuals make to the social structure. If two equivalent figures at CADC were replaced with Joyce and Maya, it may be perceived as a much more welcoming and member-friendly environment.

CONCLUSIONS: SUMMIT AND ABRAMSON

Overall, many of the issues that present themselves in Abramson's analysis of ADCs are also evident at Summit. Both are similarly organized, and the lack of resources restricts the level of engagement possible. Due to structural factors, both institutions draw employees from relatively small pools that offer few rewards in comparison to other occupational paths. Both aim to assist both the CG and CR, but CADC falls short in their stated goal to improve the lives of their members because the structural constrains cannot be overcome

My analysis of Summit finds that while not fully meeting this member-centered goal, certain factors allow it to be more successful than CADC appears to be. First, the prevalence of volunteers allows Summit to create more specialized activities and opportunities for individual-level engagement. Additionally, the micro-level characteristics of those involved in the system, mostly Joyce and Maya, allow the environment to be more lively and inviting than other similarly-structured institutions seem to be.

Chapter 7: Conclusion

SUMMARY OF THE STUDY

This study explored the process of providing care for older adults, especially those suffering from dementia. While the past 35 years of research have give us a deeper understanding of the help that unpaid family caregivers provide, highlighting the stress of care and the differing ways that families handle challenges (Zarit & Reamy 2012), the present study analyzes the care process through the focus of skill development and ADC utilization. Using a "caregiver career" perspective based on concepts developed by Becker (1961; 1963) and Pearlin (1999), the study outlined the progressive aspect of caregiving, beginning with a series of catalysts that thrust an individual into the care process and continuing as the individual gains knowledge of caregiving. Instrumental to this framework is the presence of ADCs; this study outlined the way ADCs can mitigate stresses associated with caregiving while also serving as a source of information acquisition for the CG and providing a beneficial environment for the CR. In all, this framework details the aspects of "successful care" by 1) outlining how primary CGs develop caregiving knowledge and skills, and 2) specifying the aspects of Summit that work well in providing a positive institutional care environment.

More specifically, the process of care was analyzed through four lenses:

1. What are the micro-level family dynamics associated with caregiving? How do these interactions evolve throughout the care process?
2. How do CGs seek help when care needs arise? Why do these patterns influence who does and does not use ADC services? What structural components shape ADC vs. non-ADC utilization?
3. How is caregiving literacy developed?

4. What characteristics of Summit help it operate as a facility that is so well-received by members and CGs?

To complete this research, I spent 18 months volunteering at Summit ADC and interviewed 19 CGs. Together, this data allowed me to analyze the care provision from multiple angles and develop frameworks to explain the social processes present.

TYING IT ALL TOGETHER

In Chapter 3, this study explored the micro level family dynamics of care. This involves the CG's personal outlook on care provision, their interactions with the CR (and how it changes pre- and post-caregiving career), and managing relationships with friends and the workplace. While most CGs felt that they were in a 'good place' now, they detailed the immense transitions and adjustments they had made to accommodate the CR. Although there were difficulties along the way, most CGs noted that they also received a degree of support (practical and/or emotional) from others, whether it was from individuals or institutions. This assistance is crucial in the tightly wound schedules and lives of many CGs, since their social lives, leisure activities, and other formerly important aspects of living may have been adjusted or eliminated.

Caregiving can foster positive, negative, and ambivalent emotions within the CG. At times they may feel joy because of the comfort they provide, but they can also resent the fact that they have had to leave behind other aspects of their lives to provide it. This can be especially difficult if the CR undergoes significant changes in mood and personality. However, for those who were affiliated with Summit, both CGs and CRs were satisfied with the results.

Chapter 4 examined the pathways into ADCs. It began by first outlining the subjective nature of living with dementia; an individual CG's threshold for seeking help varies by situation and context, so the point at which someone seeks help differs.

Additionally, access to resources such as information or capital may influence what type of help they seek.

When it comes to ADC utilization, I found that ADC utilization follows a pattern I call Echoed Help Seeking. CG initially consult informal networks when the care need arises, eventually moving on to consulting more formal networks at the CR's condition progresses. Although many are seemingly good candidates for local ADC services, their doctors rarely inform them of such interventions. It is only after utilizing their informal network post-formal help seeking that CGs discover this intervention. The Echoed Help Seeking process suggests that there is a disconnect or lack of knowledge exchange between ADC providers, doctors, and individual CGs.

Most CGs in the sample who did not utilize ADC services had characteristics that allowed them to provide care differently. For instance, many of them were voluntarily unemployed or had great flexibility in their jobs. Such privileges give the caregiver more potential options for providing care only at home.

Chapter 5 outlined caregiving literacy. I define caregiving literacy as "the knowledge of and competence in proper care for someone with dementia; includes knowing the causes and symptoms of the disease and the best way to treat, maintain, and/or relieve the effects of this condition given the care recipient's specific needs." Initially, most CGs have limited knowledge of the responsibilities needed and the way to navigate certain institutions. However, through a variety of strategies such as classes, support groups, and ADCs, they build their sense of understanding and skill. By building caregiving literacy, CGs are able to progress along the caregiving career with more confidence and awareness of the process at hand. Although no one is ever fully competent, improving one's understanding of dementia and dementia care can ease the twists and turns associated with the disease.

Finally, Chapter 6 transitions to an analysis of Summit. Previous research has indicated that ADCs generally do not have the resources to accomplish all of their stated goals. ADCs tend to have a dual focus: 1) improve the quality of life for the members, and 2) provide respite for the CG. In Abramson's (2009) analysis of an ADC, he found that these goals were fundamentally flawed because the configuration of the ADC's staff and finances could not live up to this standard; thus, it becomes only a respite center. In my analysis, I found that while Summit faced some of these same challenges, it was more successful in approaching these goals. The first reason is that Summit features a strong influx of helpers and volunteers throughout the year, giving them more manpower than a typical ADC may have. Additionally, the individuals at Summit are strongly committed to its goals, creating a "greater than the sum of its parts" scenario where despite having a similar design as the ADC in Abramson's study, Summit is able to achieve more.

A running thread throughout these chapters is the importance of support of all kinds. As stated in Chapter 1, having a strong convoy throughout the life course can be beneficial in a variety of ways. Structural or institutional support, such as that provided by ADCs or other community organizations, strengthens a convoy by giving the CG more external options for care provision. A facility such as Summit adds a place where CRs can be well taken care of while the CG fulfills other obligations They also help build knowledge and skills that strengthen caregiving literacy. From an interpersonal standpoint, support from family, friends, and acquaintances strengthen one's convoy by providing them with the instrumental, emotional, and educational support needed to successfully navigate the caregiving career. Even access to tools such as the Internet opens up a stream of resources and knowledge that can make the care process less burdensome.

Implications

In outlining important areas for future research, Zarit & Reamy (2012) posit that two aspects of care should be analyzed further: 1) what are the goals of interventions and services? 2) are they working as intended, or do they need reform? Based on my analysis of Summit, the objectives are clearly aligned with the general goals of ADCs nationwide: provide a safe, stimulating, and productive environment for members while simultaneously providing respite to CGs and providing them with useful knowledge. As mentioned in the section above, ADCs are not always able to meet these goals for a variety of reasons.

Due to this, there is an argument to be made that reform is necessary. Understaffed and underfunded ADCs are only fulfilling half of their stated purpose, and the members are spending the majority of their time from Monday to Friday in a less than stimulating environment. If this is the case, ADC reform is needed. However, I find evidence that even in the midst of these difficult circumstances, the right mix of individuals can bring out the best of what ADCs have to offer. It's not a simple task, since most ADCs cannot afford to hire the best applicants in their field, often staffing their facilities with individuals with no explicit skills for elder caregiving. However, it is possible. When this mixture of factors is present, ADCs can fulfill their goals in tremendous fashion.

Another implication of this study goes toward answering an important question: do ADCs delay institutionalization? Based on my analysis of Summit, they can indeed delay institutionalization in family units where other conflicting commitments interfere with care. For the non-ADC participants in the sample, institutionalization was often a faraway thought since the context of their lives made it easier to provide care. But many of those in the ADC sample praised Summit for allowing their CRs to remain at home when they thought no other options are available. Many of the CRs in this situation are at a unique stage of cognitive decline: too impaired to live alone, but not impaired enough to necessitate constant, formal care. Additionally, many of these CGs have jobs that keep them away from home during standard hours, causing a dilemma in their caregiving careers. By utilizing Summit, these families are able to provide care during their off hours while still having time to work, care for their families, etc. when the CR is at Summit.

Institutional and Policy

According to the NASEM Report (2016), "despite their critical role, family caregivers of older adults are often marginalized or ignored by providers and systems of care." Care is often fragmented, and there can be a disconnect between CGs, health professionals, and providers of long term services and supports. CGs and CRs have a general lack of shared understanding with care providers about the roles and responsibilities associated with providing care. For instance, the report states that only one-third of CGs had ever been asked what was needed to care for their relative by their doctors. The report suggests that there needs to be a movement toward shared decision making for all involved: more communication and deliberation between CRs and medical professionals, featuring an interactive process of reflection and discussion. This can lead to more person and family centered care, where proper assessments of CG capabilities and needs are present. Most importantly, the proper systematic identification of CGs is an essential aspect of delivering the most beneficial care and interventions; doctors and organizations such as ADCs must reach CGs and inform them of the most favorable course of action for their particular situations.

My study supports these findings, indicating that this trend is very much alive in the Central Texas area, and it is perhaps prevalent nationwide. The pattern of Echoed Help Seeking indicates that CGs are often not receiving information about the most valuable interventions available to them from doctors, instead having to retreat to informal networks before obtaining this knowledge. In line with the NASEM Report, I suggest that partnerships between medical professionals, ADCs, and CGs need to be stronger. The dissemination of knowledge must be freer and more readily available, providing CGs with a clear vision of the best course of action when confronted with the caregiving career.

From a policy standpoint, it is clear that social services such as ADCs are often crucial to the caregiving career and delaying institutionalization for those with dementia or other health issues. Recently, federal lawmakers and other politicians at the national level have called for Medicaid reform; some of these suggestions, such as structuring Medicaid as a block grant, could slash finding and leave millions uninsured (Park 2016). If such goals continue to be pushed by lawmakers, we may see a very different ADC system in the future. Medicaid provides healthcare and other medically related coverage to millions, and its reduction or elimination could be disastrous for many families like the ones at Summit. As I type this sentence, the majority of people at Summit are there due (at least in part) to Medicaid assistance.

Although it may be the cheapest alternative to more formal institutional care, Summit still costs $60 daily, which would be a lofty price for many American families to pay. The elimination of assistance programs would shift the burden of these costs to individuals; if they cannot pay, but formal care is also not an option, the reconfiguration of roles within a family unit may be necessary. Shifting work hours, utilizing more informal care networks, or simply leaving elders at home alone may become necessary. The same factors cited by so many interview respondents of why they appreciate Summit so much would force them to made difficult decisions. Using Summit allows many CGs to work regular hours, but if state support for ADCs is cut off and the cost shifts downward, this flexibility is no longer an option. Systems such as Medicaid help keep ADCs affordable for families, and if these supports are reduced or eliminated, families may be forced to make due in the face of bleak options.

LIMITATIONS AND FUTURE DIRECTIONS

There are limitations to this study that should be considered. The scope of the study is small; only 19 caregivers were interviewed, 10 of which utilize ADCs. This makes it difficult to draw large-scale conclusions about the general population or caregiving as a whole. Additionally, fieldwork and observation took place in locations that are all affiliated with the same nonprofit organization, all situated in Central Texas. Indeed, Central Texas is a unique case; there are 464 ADCs in Texas (DAHS 2018), and only two are located in the area.

The small scope of this study presents the possibility that these results are unique to one geographical area or that other regions do not experience these trends on the same scale as was observed in this study. By studying one organization, I only observed the inner workings and organizational structure of a single entity among thousands of ADCs in the United States. With this small scope, I have no way of inferring that all ADCs are operated in the same way, or are even remotely similar to Summit.

Regarding the small interviewee sample, the nature of ethnographic methods makes it difficult to study large groups at once. The scope of the project was not large enough to accommodate a larger sample. However, although the number of participants is relatively low, I was able to gain a deep understanding of their life histories and experiences. The small sample size limitation is somewhat offset by the depth in which I could analyze the day-to-day caregiving process that the participants detailed in interviews.

Similarly, spending 18 months at Summit gave me a nuanced understanding of how the organization works and how care is distributed to the members. Despite only having one major field site, I was able to draw conclusions based on hundreds of hours of observation. Other ADCs may operate slightly differently, but through this study I am able to note precisely what it is about Summit that makes it operate well.

Another limitation of the study is that the sample is majority highly educated, middle to upper middle class, and white. This does not represent the "typical" caregiver, in that many people who have less education, lower SES, and are racial/ethnic minorities are caregivers, and their experiences may not have been reflected in these results. It should be noted that while the interview sample is not an accurate cross section of the United States population, it does allow us to view the caregiving career from a certain demographic perspective. My analysis is the narrative of relatively affluent individuals who all live within driving distance of one of the largest metro areas in the United States, and it is important to understand that perspective. Their situation, taken as a whole, cannot be applied perfectly to those who may have less education or income, but understanding the care process for all demographics is important. Based on my findings, even those with relatively easy access to information and technology have a hard time understanding all of the available care options and strategies. Armed with this knowledge, we can begin to implement more accessible and consistent information flows throughout communities, not only operating under the assumption that less advantaged communities are the only ones who would benefit from targeted efforts.

As a whole, while legitimate criticisms may be made about the small sample size and issues of generalizability I view this study is an entry point to the analysis of formal and informal help seeking as it specifically relates to ADCs, and future studies should expand on these observations. The trends outlined in prior chapters are in no way a declaration as the official trajectory of caregiving, but they present a framework that can potentially explain some of the patterns we observe in caregiving and ADC utilization. These concepts should be tested with larger sample sizes of caregivers, both those who utilize ADCs and those who do not, to determine whether the conclusions of this study persist. Additionally, ADCs in other regions should be studied to explore whether or not the same operational processes are present beyond the scope of this study.

In regards to more specific frameworks, the following extensions of this study would be useful pursuits:

- How does the concept of Echoed Help Seeking hold up when applied to a different population? Additionally, is this a small-scale phenomenon or is it generalizable to larger segments of the population? Also, do less affluent pockets of society engage in the same process of help seeking? More extensive quantitative research is needed to gauge the generalizability of this concept to diverse population.
- Additional qualitative research into the structure and day-to-day operation of other ADCs would greatly supplement this study. How unique is Summit in the daily environment created by the particular individuals present? One finding from Chapter 6 was that despite institutional limitations, Summit is able to maintain its environment due to the specific people involved. Is this typical, or is Summit an outlier? A different way to approach this question would be to study Summit at later time when there has been significant turnover for both staff and members.
- Expanding the interview sample to include multiple people in a caregiving family unit could introduce valuable nuance to the narrative. Although CGs were forward in sharing their stories, for the most part I understand their situation from one perspective: their own. Bringing in the others involved could be insightful. For

instance, the narratives discussed in prior chapters regarding conflict with other family members could be better understood by speaking to these individuals. While I expect the general account would remain the same, they may provide perspective and insight into aspects of the caregiving process that were missed or glossed over in the initial analysis.

- Based on my review of the literature, the family dynamics aspect in many of the interview participants is common for both the dementia and non-dementia CGs. However, my sample did not include anyone who cares for a child or sibling. Are micro-level interactions and adjustments similar for these groups? If so, how? Furthermore, is ADC participation and satisfaction from child or sibling CGs comparable to those in this study's sample?
- How does caregiving literacy differ for those who are second-generation dementia CGs? Only a few individuals in the sample had ever had a close loved one suffer from dementia, and none of them had ever been the primary CG for that person. What are the knowledge acquisition trends that exist for those who have been dementia CGs before? For instance, do they build on the skills they already have, or does the process involve "unlearning" some things that worked for their first CR to properly care for the second? I hypothesize that it is a little bit of both, but what are the nuanced patterns in this process?

FINAL WORD

In all, becoming a CG is often a tremendous transition for the person providing primary care, but also for those around them. In this study, I attempt to build a framework around the caregiving career explaining how it progresses. This progression may involve transformations in micro-level family interactions, reorganization of work and social life, acquisition of new knowledge and skills, and an introduction to a set of institutions that had never been encountered before. Through it all, the majority of CGs find a way to make it work. Many feel like they are always on a road of uncertainty, given the nature of the illnesses and injuries their loved ones suffer from. This study sought to frame this journey in the context of learning how to provide care in the best way possible, for both the ones receiving care and the ones providing it.

CONFLICTS OF INTEREST AND FINANCIAL INFORMATION

No conflicts of interest were identified in this research. No outside funding was used in the implementation of this research project.

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