

THE SOCIAL LIVES OF INFORMAL DEMENTIA CAREGIVERS

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ABSTRACT

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THE SOCIAL LIVES OF DEMENTIA CAREGIVERS

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In the coming decades, there may not be enough professional caregivers to meet the needs of elderly and disabled persons; family and friends will take on more informal care roles than ever before, with great social impact, yet the social literature lacks consistency and breadth. This exploratory, quantitative study organizes the disparate social literature on caregiving and dementia care and suggests a critical theoretical framework to interpret social factors more fully. Utilizing the *Caregiving in the U.S.* dataset from 2015, three hypotheses test this framework for a dementia care population to identify variable combinations that exert outsized influence on care outcomes. Findings confirm two hypotheses: people of color tend to develop dementia far earlier than whites and persons who are marginalized in multiple ways tend to perform more activities of daily living; these findings demonstrate a role for intersectionality and queer subjectivity in dementia care analyses and interpretation.

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## CHAPTER I

### INTRODUCTION

Along with an increase in life expectancy, many nations have begun to see an increase in conditions associated with old age, especially dementia. A person who develops dementia experiences progressive, irreversible cognitive decline without necessarily recognizing the change. As such, dementia has a deeply social impact, altering the way others view and interact with the person and creating dependence upon others that only increases over time. Those who serve persons with dementia — whether family members, friends, or domestic workers hired for the purpose — are their caregivers. Caregivers may work to maintain or improve the quality of life of those they serve (whether that service is paid or unpaid), but when their support cannot stabilize or improve the condition (as is the case for dementia), it can be hard to reconcile the care role with cultural, economic, and familial notions of success and vocation. Research on dementia and on caregiving at large show that outcomes for the caregiver and care recipient are deeply intertwined with social facets of their lives: status, identity, and personal support, among others (Bruhn & Rebach 2014:15-29, 70-118). Unfortunately, research into caregiving and dementia care has not necessarily developed its social facets.

In this exploratory, quantitative study, I review social scholarship of caregivers, dementia, and dementia care dyads, then test a social inquiry into dementia care while applying intersectional and queer theories by Crenshaw and Halberstam. This chapter introduces the core topics, terminology, and approach.

## CAREGIVING AND DEMENTIA CARE

As humans live longer, particularly in industrial or post-industrial nations (see Bell in Grusky & Weisshaar 2014:1066-1077), there is usually an unspoken expectation that the portion of years where a person can be vibrant and independent are also expanded (Lock 2002:33), however this is so far not the case. Publishing with the National Institute on Aging and the National Institutes for Health, the World Health Organization (2011:6-8) reports developed nations are but the first to face unprecedented proportion and growth for elderly and disabled populations. This phenomenon has raised the visibility of persons whose roles and responsibilities were hidden, presupposed, until recently: the caregiver.

Elders in the U.S. can now live for decades after retirement age, but their health has not kept pace (Eifert et al. 2016; cf. Halberstam 2005:153). However, caregiving is not only about elders; over a quarter of people ages 18-65 in the U.S. have a disability or chronic condition, and this figure is also growing (Scales et al. 2019:21). Patients with conditions that were once a death sentence (such as cerebral palsy or AIDS) now have life expectancies that approach those of the general population. Caregiving can also include recovery support for injury, temporary illness, and surgery. The proverbial broken leg takes 6-8 weeks to recover, during which time an otherwise healthy adult may rely on others for transportation, groceries, bathing, and logistics; the recovery time for life-threatening forms of cancer or from a traumatic brain injury, meanwhile, can last well over a year and forever change family roles. Care outcomes tend to worsen for caregivers as frequency of tasks and duration increase (Hunt et al. 2017:18-22) — these factors are also linked to a higher risk of elder abuse (Schulz & Eden 2016:107-108).

Giving care to the sick, the elderly, and the injured is a significant social behavior among humans (George & Ferraro 2016; Montgomery & Kosloski 2013; Schulz & Eden 2016:86); this significance has not always been assumed, however (Seaman 2018). Since the beginning of the Industrial Age, changed standards of health, hygiene, and even violence have lowered death rates, while biomedical discoveries have enabled life to be prolonged, particularly near its end (Bruhn & Rebach 2014:20). As (white, able-bodied) middle-class women — traditionally caregivers of both children and the infirm (Schulz & Eden 2016:50, 53-55) — gradually joined the workforce (Suitor, Gilligan, & Pillemer 2016), so too did families begin to spread out rather than living geographically close. Urban complexity and dual-income priorities also led to lower birth rates, leaving aging parents with fewer children to serve as caregiver; a growing portion of elders have no children at all (Schulz & Eden 2016:61-62).

Estimates range from 17-39 percent of U.S. adults giving some type of informal care to another adult each year (Fox, Duggan, & Purcell 2013), of which dementia care accounts for nearly a quarter (Hunt et al. 2017:6); other common ailments including recent surgery, cancer, and loss of mobility (Hunt et al. 2015:29). The tasks involved in caregiving depend upon the condition of the care recipient, but tend to be measured in two types: activities of daily living (ADLs) and instrumental activities of daily living (IADLs; Hunt et al. 2015:8; Roth, Fredman, & Haley 2015; Schulz & Eden 2016:45). ADLs are those activities that are necessary to live: feeding oneself, minimal hygiene, or being able to move oneself short distances. IADLs, on the other hand, are those tasks that are necessary in order to function in society: obtaining groceries and preparing meals, managing finances and housework, and

arranging support. High-need caregivers number over 8.5 million, or 3.5 percent of all adults over age 20 (Schulz & Eden 2016:50, 306; Vitaliano et al. 2011); care is considered "high-need" in any case involving assistance with two or more ADLs, cancer, probable dementia, or once daily care is required for longer than 2 years (Schulz & Eden 2016:74, 82-83). The endurance of informal caregivers grants a silent economic and logistical reprieve for their doctors and communities, but not without costs for the caregiver (Bruhn & Rebach 2014:160-164; Schulz & Eden 2016:92-96).

In the U.S., caregiving is predominated by care for elders, who receive most of their care from spouses or their (middle-aged) children (Schulz & Eden 2016:50, 53-54). The rapid growth of the U.S. elder population has led to more hiring of home healthcare workers (Glenn 2010:154-160), a fast-moving corporatization of long-term care facilities (Edelman 2018), and strains in the long-term care insurance industry (Bruhn & Rebach 2014:86; Gleckman 2019; Kwak & Polivka 2014). Even if all families could afford professional support or institutionalization (Bruhn & Rebach 2014:86), the industry is not large enough to meet the care needs of elders (Gaugler et al. 2019:40-41; Redfoot, Feinberg, & Houser 2013) in the present, let alone meet projections (West et al. 2014). As was done before the separation of production spheres (Fraser 2016), families and communities are stepping up informally (i.e., without pay or training — Hunt et al. 2015:42-45) to fill this gap.

The combination of informal and formal care may not be enough (Redfoot et al. 2013; Roth et al. 2015; Schulz & Eden 2016:51-53). Baby Boomers (born 1946-1964), whose unusual size as a birth cohort is the reason for their name and official Census designation, are expected to need more care in their later years than the younger population will be able

to provide at previously observed care participation rates (Feinberg & Spillman 2019; Redfoot et al. 2013; Ryan, et al. 2012). This disparity may be a warning to future generations, or it may be unique to Baby Boomers, about whom care gaps have been predicted since the earliest Millennials were born (Kane & Kane 1980). Either way, the Boomer care gap is already emergent and changing the relationship between age and care participation; as of 2014, Millennial adults (born 1980-1996) already represent one quarter of all caregivers and 16 percent of dementia caregivers (Hunt et al. 2017:8) — the highest of any birth cohort on record of comparable age.

As with the concept of caregiving, our understanding and terminology for dementia have evolved over the last half-century. Physicians no longer believe that moderate memory loss is normal for a person at any age; the terms *senility* and *demented* have been deprecated in favor of framing all cognitive decline as some form or other (however advanced) of dementia. A syndrome rather than one specific disease (Haeusermann 2017), dementia indicates a gradual degradation of the person's synapses. Although some rare and externally traced types of cognitive decline can be reversed (Dwolatzky & Clarfield 2003), the overwhelming majority are associated with aging and general health, and these are irreversible (Gaugler et al. 2019:8). Irreversible dementias are collectively called Alzheimer's Disease and Related Dementias (ADRD), although Alzheimer's itself is now a catch-all for cases of irreversible dementia that do not follow other, more specific pathologies (such as frontotemporal or Lewy body dementias). Our current understanding of ADRD pathology indicates that most people who will eventually develop dementia begin synaptic decline as much as twenty years before symptoms are noticeable (Gaugler et al. 2019:5); once

symptoms appear, cognitive decline can affect any or every aspect of a person's ability to learn and remember, even altering their personality (Keefe 2017).

Dementia is diagnosed in 10 percent of all U.S. elders over age 65, and early onset dementia is estimated to affect another 200,000 persons under age 65 (Gaugler et al. 2019:17). The proportion of U.S. elders diagnosed with dementia appears to have plateaued, yet the numbers continue to grow as Baby Boomers age (Gaugler et al. 2019:19-23). Researchers note that the trajectory and care of early onset dementia can be dramatically different from other forms, especially Alzheimer's (Caceres et al. 2016). There is no cure or treatment for ADRDs in sight, only medications that can ease the descent (Gaugler et al. 2019:10-11); from diagnosis forward (maybe even earlier), the person with dementia grows increasingly dependent upon others to function.

Because physical symptoms of dementia tend to come in later stages, the impact of dementia is overwhelmingly felt in social contexts, where expectations and assumptions about reality can clash due to memory loss, language difficulties, and erratic behavior on the part of the person experiencing cognitive decline (Beard, Knauss, & Moyer 2009). Supporting a person with dementia can entail anything (and, eventually, everything) from transportation and decision-making to hygiene and feeding (Gaugler et al. 2019:31-33). Care for persons with dementia is said to be among the most challenging of all caregiving situations, and accounts for nearly half of all elder care (Gaugler et al. 2019:31-32).

Out of every five dementia caregivers, two report being solo caregivers (Hunt et al. 2017:23), but feelings of isolation are common among others as well (Schulz & Eden 2016:104-105). Studies associate social isolation with higher stress from caregiving (called

“caregiver burden”), especially when care lasts longer than 2 years (Schulz & Eden 2016:306; Vitaliano et al. 2011). Even professional dementia caregivers report higher levels of isolation than other caregivers (Morgan, Innes, & Kosteniuk 2011), exacerbating the infrastructural strains discussed above.

### *Terminology and Clarifications*

The following terms will be used in this study:

*Caregiving*: the act of supporting another person through daily living activities. The term *caregiving* became necessary in the latter half of the twentieth century to differentiate it from *caretaking* (the care for a place, a thing, or some other object). Although the term is common in U.S. research (U.K. research often uses *carer* and dementia advocates prefer *care partner*), the parameters of its application are inconsistent and rarely explained, leading to wide disparities and conflicts between findings; studies that sample only adults who have provided some amount of care some time in the last year will demonstrate very different findings from those that include care of children with developmental disabilities but sample only caregivers who served for six months or more. (Child-rearing specialties sometimes substitute *caregiver* for *parent* since the term is more inclusive, but the raising of children without illness or disability has its own connotations and fields of research and is consistently excluded from caregiving research.) For this study, the following terms are used interchangeably: care/caregiving/giving care/care work.

*Caregiver*: any person who performs caregiving; often linked to the person(s) for whom they care through possessive pronouns (e.g., “Ed’s caregiver”). The term remains controversial outside academia — Bruhn and Rebach report that “as many as 75 percent of

family caregivers who provide personal care do not self-identify themselves as caregivers until personal care and homemaker assistance becomes an economic and psychological burden” (2014:7) — yet there is evidence that intense caregiving experiences alter caregivers’ self-perception (158-160).

*Care Dyad*: the pairing of a care recipient and their caregiver (usually primary). As will be discussed in the literature review, many studies discuss care dyads while focusing their inquiry or analyses on either the caregiver or the care recipient, not both. The term *care dyad* is here utilized in the interest of reifying the social nature of care work.

*Formal and Informal (Care)*: a distinction made between care/givers as to whether care work is paid (formal) or unpaid (informal), with implications that formal care also involves training and supervision while informal care comes from family or friends. Efforts to compensate informal caregivers (Eifert et al. 2016; Glenn 2010:174-175) and inconsistent parameters for what constitutes “care” (Hunt et al. 2017:6n) are blurring this boundary. Professional caregivers are outside the scope of this study, so all care that is not otherwise specified can be presumed to mean informal care.

*Primary Caregiver*: an informal caregiver who assumes the majority of responsibility in at-home, day-to-day care, regardless of others’ support or decision-making; if a care recipient stays in a medical or long-term care facility, family (or other support) legally appoint a primary (informal) caregiver to coordinate professional services.

*Secondary Caregiver*: any informal caregiver who is not primary or solo. Although social support and distribution of roles have received some attention, research has yet to develop the role of secondary caregivers in dementia or other care contexts.

*Care/Support System/Network*: the care dyad and all who support its caregiving efforts. As no standard yet exists, this study uses *care* as described above and *support* only to refer to the direct social support or logistical assistance given to care dyads; similarly, I use *network* for only family and social involvement, whereas *system* connotes active participation and may including medical and other intervention practitioners.

*Elder/Senior/Old*: description of persons who are socialized as having an advanced age. In the U.S., 65 is a common cut-off, beyond which everyone is an *elder*, a *senior*, or an *old person*. *Elder* is most common in social research, *senior* is more popular in marketing, and *old person* is considered impersonal/impolite.

*Intersectionality*: a theoretical paradigm that explores the consequences for persons who are subjected to multiple social disparities. Rather than merely calculating material outcomes in a straightforward computation, intersectionality examines the distinct ways marginalizations interact with one another (often, but not always, amplifying material outcomes) within a specific context; recognizing the complex nature of discrimination and systemic oppression, intersectionality rejects transposing sets of intersections from one scenario to another, instead requiring consideration of relevant lived experiences.

Caregiving is a social phenomenon that reflects political, cultural, and economic priorities from every level of society (Bruhn & Rebach 2014:5; Schulz & Eden 2016:59-66); as such, this and other studies utilizing a U.S. sample (even secondarily) must center studies of the local population and not uncritically conflate it with others. Therefore, only studies on U.S.-based samples are referenced. In the interest of person-led praxis, the following terms will be favored over other conventions where possible (i.e., not quoting or citing specific

materials): Black or Black American over African American; LGBTQ over LGBT; men and women over male and female; and people of color over “minorities.”

#### PROBLEM STATEMENT

The purpose of this study is to explore the complex social interactions that affect informal dementia caregivers while demonstrating relevant quantitative and sociological approaches to the topics of dementia and dementia care. This will be accomplished through a critical literature review, followed by testing hypotheses over some of the socially determined niches of dementia care. These three hypotheses will be tested using the 2015 wave of National Alliance for Caregiving’s (NAC/AARP) *Caregiving in the U.S.* via multivariate linear regression.

#### RATIONALE

This thesis draws from many disciplines to raise critical questions about how caregiving has been researched and how future research may be organized, suggesting a theoretical framework is necessary to connect and interpret dementia care across a fuller range of social interactions, from the personal to the systemic. This study adds to sociological literature on caregiving and proposes a useful theoretical framework for interpreting dementia care. It is the first study to apply intersectional quantitative analysis to the topic of dementia caregiving, and its findings will inform the work of communities, medical personnel, and service practitioners in the position of serving dementia caregivers. Pointing a more social lens on dementia care will also advance our contemporary response to one of sociology’s fundamental problems: Durkheim’s question of solidarity.

## STRUCTURE OF THE THESIS

This study introduces and complicates literature and research practices around caregiving, particularly dementia care. In Chapter 2, a literature review shows how inequalities in care dynamics and lack of disciplinary grounding have come together to normalize research that does not adequately address the social factors in dementia care. Theoretical approaches to filling this research gap are discussed, with two critical theories (Crenshaw 1991, 1993; Halberstam 2005) selected to advance and interpret social meanings from the data. In Chapter 3, the dataset and methods are outlined, as well as the data and variables to be explored in analysis. Chapter 4 reports findings as obtained through controlled bivariate correlation and multivariate regression. In Chapter 5, implications are discussed and recommendations offered on future directions for dementia care research from the social sciences.

## CHAPTER II

### LITERATURE REVIEW

This critical literature review curates findings from the periphery of several disciplines to identify weaknesses and anchor dementia caregiving scholarship in a sociological framework. Research into informal caregiving in the United States is broadly introduced — including demographic patterns, trends in methodology, and predictions — followed by a summation of research specific to dementia care and how dementia care dyads may constitute a unique social system. Multiple theoretical approaches are reviewed for depth and relevance in developing this connection, with critical theories by Crenshaw and Halberstam selected to advance the present analysis and three hypotheses introduced for testing.

As will be elaborated in the Theoretical Framework, social literature has not been standardized for the topic of caregiving; instead, caregiving is a diffuse topic, often secondary to relevant biomedical conditions or broad, decontextualized demographics. While the focus here is caregiving for one condition — dementia — there, too, literature often lacks the theoretical groundwork to assert a focused body of work; rarely in the literature (and never with coordinated standards) do studies elucidate the care dyad, its members, and its support system outside of sweeping biomedical and public health outcomes.

#### INFORMAL CAREGIVING: AN OVERVIEW

In this section, the history and literature of informal caregiving are broadly

introduced. Despite growing belief that caregiving is innate in humans, the term and its research paradigm are less than a century old, only recently differentiated from other responsibilities by improved medical care and shifting family and gender dynamics. Demographics are presented, with health and income inequalities appearing to affect both who needs care and who provides it. Research into family dynamics is discussed, although there is limited qualitative research (and little research of any orientation for non-family caregivers). Caregiving research trends are reviewed and found to demonstrate problems in design and generalizability.

#### *Nationwide Research Trends and Findings*

Research on caregiving emerged by the 1980s (Apesoa-Varano et al. 2015; Roth et al. 2015; van Durme et al. 2012), with early and ongoing attention to how informal caregiving can negatively affect a caregiver's physical, emotional, and/or financial wellness (Beard & Fox 2008; Bruhn & Rebach 2014:161; Secher 2013). Caregivers may face greater risks than non-caregivers for stress (Crimmins & Vasunilashorn 2016), isolation (Adler & Mehta 2014; Musich et al. 2017), depression (Roth et al. 2015), relationship challenges (Schulz & Eden 2016:104), and early mortality (Bruhn & Rebach 2014:162-163; George & Ferraro 2016; Roth et al. 2013; Schulz & Eden 2016:100), yet caregiving is not without its positive aspects (Pinquart & Sörensen 2003; Roth et al. 2015). Negative consequences for caregivers appear to be moderated by the caregiver's age, race, and gender (Bruhn & Rebach 2014:111; Schulz & Eden 2016:63). Studies link social support for the caregiver to better outcomes for the care recipient (Kelley, Lewis, & Southwell 2017).

Most informal caregivers come from the care recipient's immediate family according

to availability and expectations of the relationship (Cornwell & Schafer 2015); income may be a factor as well (Bruhn & Rebach 2014:86). Available spouses are the default caregiver; selection among adult children varies by the size of the family, genders of the adult children and the parent, and individual availability or willingness (Davey & Szinovacz 2008; Sutor et al. 2016). Siblings, grandchildren, and other family members care less frequently, with non-relatives giving care up to 15 percent of the time (Hunt et al. 2015:20; Nichols et al. 2011). Attempts to discern patterns in caregiver selection remain scattered, but family role and having a close relationship with the care recipient seem to overshadow individual personality traits (Cornwell & Schafer 2015; Davey & Szinovacz 2008; Pillemer & Sutor 2006; Sutor et al. 2016). Most caregivers see their role as a duty, not an option (Hermanns & Mastel-Smith 2012), yet the 50-60 percent of caregivers who report not having a choice are at higher risk for adverse outcomes (Schulz & Eden 2016:56, 109). The proportion of care provided by families has slowly declined since the 1980s (Nichols et al. 2011), leading to explosive growth in professional and institutional care (Bruhn & Rebach 2014:20; Eifert et al. 2016; Kane & Kane 1980).

Research into caregivers tends to favor analysis of governmental datasets or structured, public-interest surveys that report broad patterns from a nationwide view (Feinberg & Spillman 2019; Kim et al. 2018; Raschick & Intergsoll-Dayton, 2004). These large-scale studies set the foundation for predictions, trajectories, and policies toward caregiving from a macrosociological level (Apesoa-Varano et al. 2015; George & Ferraro 2016), but overshadow microsociological studies into the nuances of care dynamics that may challenge existing theories, methods, and assumptions (Apesoa-Varano et al. 2015; Seaman

2018). Condition-centered studies of caregivers, meanwhile, tend to assert the perspectives of medical practitioners and intervention providers (recent examples include Bailes, Kelley, & Parker 2016; Cloyes, Hull, & Davis 2018; Gitlin, et al. 2017; Gouin et al. 2016; Zhang & Lee 2017) instead of care dyads or their families, leading to studies from the nursing field that attempt to bridge the gap (Bruhn & Rebach 2014:22; Koehly 2017).

Caregiving is not generally regarded as a public policy priority, so efforts to improve the visibility of caregiving often convey its scope in large dollar figures, usually either the cost or savings to society (Bruhn & Rebach 2014:185-186; Schulz & Eden 2016:131; Scommegna 2016). “Cost to society” is an estimate of the economic impact of caregiving by calculating what income, productivity, or career advancement adults theoretically sacrifice in a given year to become caregivers (Cook, Snellings, & Cohen 2018; Schulz & Eden 2016:127-131); “savings to society” estimates what cumulative healthcare costs are avoided by families, governments, or the greater healthcare system as caregivers prevent more expensive interventions. Both models reduce the concepts of wellness and care to dollar amounts and may fail to report in a way that is locally relatable by communities and families (George & Ferraro 2016).

The most common instruments in caregiving research are scales of *caregiver burden*, which quantify the stress or intensity of caregiving experiences (Beard et al. 2009; Bruhn & Rebach 2014:109; Hunt et al. 2015:7-8). Some of these instruments count ADLs/IADLs, the number of hours spent providing care, or some combination of the two (Bruhn & Rebach 2014:131; Hunt et al. 2015:39-40; Pinquart & Sörensen 2004). Caregiver burden is also a component of larger constructs, such as the Marwit-Meuser Caregiver Grief Inventory

(2002); however, no measure of caregiver burden or experience has yet become an academic or intervention standard. Collectively, these instruments indicate that burden negatively affects caregivers' physical and emotional health (Hunt et al. 2015:7-8) and can lead to "caregiver burnout" (Hermanns & Mastel-Smith 2012; Nichols et al. 2011; Schulz & Eden 2016:34-35), but unexplored factors outside the care dynamic also play a role (Hunt et al. 2015:12-13; Roth et al. 2015).

Caregivers are notably more vulnerable to negative health outcomes if they lack social support or coping skills, but both members of the care dyad can suffer if a caregiver's subjective assessment of the care situation is poor (Bruhn & Rebach 2014:154-157, 163). Alternately, higher income, more education, and legal marital status seem to provide a protective effect against worse health outcomes (George & Ferraro 2016); social and other forms of support seem to help diminish some of the stressors of dementia care by improving adaptability (Roth et al. 2015). Caregiver burden and other measures reinforce that caregiving interacts not only with health status but with socioeconomic status, perpetuating inequalities.

### *Caregiving and Inequality*

Care dyads are subject to the same social forces that create health disparities. Aging, disabilities, and caregiving reflect economic and social stratifications that not only compound but exacerbate one another (Bruhn & Rebach 2014:20, 84-93; George & Ferraro 2016; Richardson & Brown 2016; Schulz & Eden 2016:61). Notably, not only the health of the care recipient is at stake, as caregivers and care recipients both demonstrate health vulnerabilities from care circumstances; these are also mediated by gender, race, and

socioeconomic factors (Apesoa-Varano et al 2015; Bruhn & Rebach 2014:87, 116; Cook et al. 2018). While many of these disparities mirror the patterns of social status and health generally, caregiving is especially susceptible to social dynamics of gender and age; furthermore, care dyads interface with race and LGBTQ status in unique, sometimes counterintuitive ways.

Overall, gender norms center women as primary informal caregivers (Apesoa-Varano et al. 2015; Friedemann & Buckwalter 2014; Sutor et al. 2016). Daughters and daughters-in-law perform at least one-third of all caregiving (Hunt et al. 2015:6; Oliner 2011; Schulz & Eden 2016:55), with wives representing another 8-10 percent (Bruhn & Rebach 2014:87; Hunt et al. 2015:20). Adult sons who do participate in care are less likely to be married and yet tend to contribute less intensively than daughters (Davey & Szinovacz 2008; Friedemann & Buckwalter 2014); husbands who take on caregiving late in life (perhaps for the first time) commonly report a loss of personal identity that may be linked with their perceived gender roles (Hermanns & Mastel-Smith 2012). Even heterosexual dual-income families depend on women to perform most care responsibilities (Bruhn & Rebach 2014:22-23; Sutor et al. 2016). The younger a woman is when she first becomes a caregiver, the greater her risk for poverty later in life (Bruhn & Rebach 2014:10, 87).

Historically, marriage, divorce, and complex blended families have affected caregiver selection and involvement (Piercy 2007; Schulz & Eden 2016:62-63); in particular, care dyads who are married to one another may gain positive effects (Bruhn & Rebach 2014:161). LGBTQ adults seem to give care at a higher rate than non-LGBTQ adults — also demonstrating equal engagement by men and women (Hunt et al 2015:81) — yet are erased

when care research is structured around the nuclear family and other cisheteronormative assumptions (Halberstam 2005:10; Olicker 2011). This gap may exclude 1 in 11 caregivers (Hunt et al. 2015:14) and disproportionately affect young adult caregivers (Flinn 2018; Hodson forthcoming); Millennials — the adult cohort most likely to come from blended families, to identify as multiracial, and to identify as LGBTQ — are taking on caregiving early and often (Flinn 2018; Fry 2017). Research has found no significant difference in the outcomes of care dyads based on the sex, marital status, or LGBTQ identification of caregivers.

People in general are becoming caregivers earlier in life than in decades past (Bruhn & Rebach 2014:9; Moon & Dilworth-Anderson 2015), reflecting perhaps the smaller sizes of contemporary families, a growing sense of idealism and service among young people (Cook et al. 2018; Pew 2015), and a relaxing of traditional gender norms for men. Younger caregivers, though beleaguered and less prepared (Brodaty & Donkin 2009), show greater physical resilience against care burden than older caregivers (Hunt et al. 2015:51, 53; Schulz & Eden 2016:101), even in cases of dementia (Hunt et al. 2017:21); however, there is concern that people born after 1980 (Millennials and Generation Z) will devote more years to caregiving across their lifespans than any previous birth cohorts (Cook et al. 2018; Flinn 2018). Older caregivers, especially those over 65 (who are more expected and expecting to give care; Scommegna 2016; Sutor et al. 2016), tend to face challenges that are more financial (Eifert et al. 2016) and physical (Pinquart & Sörensen 2003). The risk of early death is reportedly greater for older caregivers than comparable non-caregivers (Schulz & Eden 2016:100), although this finding has been recently disputed (Roth et al. 2015). Caregivers of

“middle” age (more or less Generation X) may have the best combination of resources, but also carry the greatest number of responsibilities, not least the likelihood of working full time, raising children, or even both (Berry, Apesoa-Varano, & Gomez 2015; Bruhn & Rebach 2014:4, 38).

The relationship between health disparities and care disparities is most evident among people of color, who (particularly Black men) tend to experience major illness earlier and more severely than other races (Bruhn & Rebach 2014:99). More specifically, people of color tend to demonstrate more comorbid conditions, greater ADL needs, and earlier onset of dementia when compared to whites (Angel, Mudrazija, & Benson 2015; Schulz & Eden 2016:61, 110). Rodriguez (2018) suggests that premature death amongst marginalized communities exacerbates disparities in later life. Several studies point to people of color being more resilient against social isolation and caregiver burden than whites (Schulz & Eden 2016:113), but critics note these studies may lack sufficient controls for other intervening socioeconomic factors, which can have a multiplier effect on health and life expectancy (George & Ferraro 2016). Caregivers of color, who are less likely to care alone and more likely to involve non-relatives than whites (Hunt et al. 2015:20; Schulz & Eden 2016:21), generally reporting more positive and fewer negative consequences to care (Angel et al. 2015; Schulz & Eden 2016:110); this is especially the case with Black caregivers (Apesoa-Varano et al. 2015). White caregivers tend to be older, more likely to be supported by family members, and are less likely to be employed (or more likely to be retired) than caregivers of color (Bruhn & Rebach 2014:105, 107).

Caregiving as a topic of research is neither broad nor deep, but demographic projections for the U.S. are increasingly urgent. Family and friends make up most informal caregivers, yet professional caregivers are doing more than ever before. Large-scale studies have helped define and publicize the scope of caregiving, yet they omit broader support systems. Inequalities of broader society are reflected and amplified by caregiving, but complications also exist. Women give the most care and seem to be the most vulnerable to its sacrifices, yet people of color seem uniquely protected against some of its worst consequences. Younger caregivers (i.e., Millennials) are participating in care earlier and more intensively than previous generations at their age, shifting norms and demonstrating diversity that appear poised to challenge longstanding assumptions about care dynamics.

#### *Research Criticisms and Conclusion*

Caregiving can be a difficult research topic to syncretize, spread as it is across many academic fields and approaches. Care research has no home discipline or set of methods around which to develop; often, it exists only as a niche within literature on the care recipient's condition (van Durme et al. 2012). Broad studies of caregivers, on the other hand, frequently favor conventional or convenient designs that may not fit. Scholars have noted such weaknesses in care research as narrow sampling (Apeosa-Varano et al. 2015; George & Ferraro 2016; Pinqart & Sörensen 2003), recording and analysis that oversimplify U.S. racial dynamics (Angel et al. 2015; Bruhn & Rebach 2014:110), and reporting statistics for non-probabilistic samples (Pinqart & Sörensen 2004; Schulz & Eden 2016:60; Werner, Karnieli-Miller, & Eidelman 2013). Methods get mimicked uncritically, allowing a single facet of a care recipient (such as their age, healthcare, or disease) to overshadow potentially meaningful

dynamics from their entire support network (Davey & Szinovacz 2008). Advocates are calling for more inclusion of the care recipient's perspective in care research (Schulz & Eden 2016:220-221), even in the case of dementia (Fazio et al. 2018).

Although public and public interest datasets convey the scale of informal care by counting and categorizing caregivers, these datasets only fulfill bureaucratic priorities if explored uncritically, overlooking even big-picture intimacies of caregiving. Surveys and interviews alike prefer to examine caregiving through a single unit of analysis — the primary caregiver — despite evidence that larger care networks are present and effective (Nichols et al. 2011; Schulz & Eden 2016:106). Critics note that surveying a single caregiver ignores social networks beyond the care dyad (Davey & Szinovacz 2008; Koehly 2017); the level of involvement by non-primary caregivers, the sharing of responsibilities, and the selection of a primary from several options have all been recommended for further inquiry. Examining the entire phenomenon of caregiving can be challenging because of just how unseen caregiving tends to be (Seaman 2018). Research designs that emphasize one caregiver and one care recipient dealing with one condition may not adequately reflect facts on the ground and risk furthering this invisibility. Isolation and time limitations also can make care dyads difficult to recruit, especially for lengthy interviews or observation (Bédard et al. 2001; van Durme et al. 2012), and many families from low-income backgrounds — and families of color in general — reject the construct of “caregiving” entirely (Apesoa-Varano et al. 2015; Bruhn & Rebach 2014:87, 100-105). Deeper still are the limitations of care research grounded in superficial assumptions and care ontology; studies that focus on “family care” or “elder care” or “informal care” do not necessarily define their terms consistently, or at all.

George and Ferraro (2015) invoke “the complexity of change” to endorse social aging research with “considerable audacity and fortitude,” but care scholarship lacks diversity in both designs and cases (Remler & van Ryzin 2011; Schulz & Eden 2016:56). While the over-65 population of the U.S. remains overwhelmingly white, the proportion of whites in this segment is decreasing (Angel et al. 2015; Eifert et al. 2016; combined with lower life expectancies for people of color, the concentration of racial diversity in people born after 1960 (Schulz & Eden 2016:59-60) risks functional segregation of age itself. This racialization of U.S. aging may already be underway in formal care, where 26 percent of professionals are immigrants, who are vulnerable to misinterpretation, exploitation, and mutual distrust (Scales et al. 2020). Reliance on professional caregivers nearly doubled from 2008 to 2018, and may continue to do so (Scales et al. 2020); demographers warn that the U.S. population has not grown fast enough from births alone to meet the anticipated care needs (formal or informal) of aging Baby Boomers (Kane & Kane 1980; Schulz & Eden 2016:185; Scommegna 2016).

Both quantitative and qualitative approaches risk repeating societal erasures and diminish academic rigor when they look at gender, race, and class as separate phenomena from health status, quality of life, or caregiving outcomes (Kelley et al. 2017; Lovell & Wetherell 2011; Olikier 2011). Increasingly, health in old age is being understood not as a random occurrence but as the culmination of a person’s life experiences and their socioeconomic advantages and disadvantages (Richardson & Brown 2016), but this approach is not often employed in studies of elder care. Angel et al. caution that caregiving surveys do not adequately address "the way in which social aspects of racial and ethnic diversity are affected by the life course and social policy," connecting this oversight to poor clarity of

what is meant by "social support" (2015:8; cf. Cornwell & Schafer 2015). Without far more rigorous analysis of many social factors and how they interact with caregiving, Roth et al. warn that caregiving for a sick relative cannot be demonstrated to be any more stressful than having a sick relative without providing them care (2015:310-11) — except, as is common with such critiques, in cases of dementia care (cf. Pinquart & Sörensen 2003).

A growing number of health researchers are calling for multi-level analyses that target health inequalities (Gkiouleka et al. 2018; Richardson & Brown 2016; Richman & Zucker 2019). Studies commonly differentiate “high need” care situations — including dementia (Schulz & Eden 2016:91) — for having stronger feelings of exhaustion, overwhelm, and burnout (Gaugler et al. 2019:34-36; Pinquart & Sörensen 2003; Schulz & Eden 2016:74), but the “high need” designation lacks consistent standards. The grounding of caregiver studies with theory and/or a dedicated discipline may offer better frameworks around care research, built on nuanced categories (Angel et al. 2015; George & Ferraro 2016) that will, in turn, better inform care dyads and those who support them.

Caregiving scholarship draws from a wide range of traditions, which can lead to questionable methods and results that are difficult to generalize. Scholars of caregiving and health have an opportunity to fill the gap of social meanings, particularly the interrelatedness of social inequalities and clearer understandings of social support, but to do so will require streamlining diffuse design approaches. At the same time, informal care research must expand its scope to include not only caregivers but dyads and support networks, not only health and burden measures but a layering of positive and negative socioeconomic factors and their systemic roots over the life course. Care research has an urgent need to advance, as

generational changes are beginning to outpace foundational assumptions and nationwide care gaps loom; the scale of care likely to be needed in the coming decades will have a dramatic effect on the attitudes and opportunities of Millennials and Generation Z over their lifespans.

## THE DEMENTIA CARE DYAD

In this section, dementia care dyads are explored as a unique and significant social system. Dementia care and its scholarship are outlined relative to other care dyads, followed by some exploration of research on how this system interacts with other social systems. Outcomes from these interactions are summarized and trends are detailed.

### *Dementia Care in the Context of Elder Care*

Caregiving research is often framed by the care recipient's condition, and dementia care is considered one of the most intensive and challenging forms of caregiving (Bruhn & Rebach 2014:131). Early caregiving research framed family members as “the ‘real’ victims” of dementia (Beard et al. 2009:227), and even today, “The most prevalent discourses in the US depict family caregiving as a necessary, but onerous stopgap measure until a better, biomedical solution is available” (Seaman 2018:64; cf. Cockerham 2013; Mol 2002:7-13n). Dementia caregivers report high levels of burnout (Bookman & Kimbrel 2011), as well as difficulties receiving adequate support — social or otherwise (Hunt et al. 2017:25) — yet no current or near-future treatment for dementia can significantly lower the need for people who monitor and protect people with dementia (Stites, Rubright, & Karlawish 2018). In total, nearly 6 million people in the U.S. are living with Alzheimer’s or another dementia and over three-quarters will need daily care by the late stages (Gaugler 2019:17; Scales et al.

2020). Although the proportion of elders experiencing dementia appears to have plateaued, the population of people with dementia continues to grow (Gaugler et al. 2019:23; Scommegna 2016).

Caregiving is generally considered "high-need" if daily care lasts for longer than two years, but dementia care becomes difficult much sooner and lasts an average of 4-6 years (Gaugler et al. 2019:34-36; Pinqart & Sörensen 2003; Vitaliano et al. 2011). Caregiving for a person with dementia never stabilizes for long, but gradually expands in scope until the care recipient loses mobility or dies. Both the intensity and the duration of care increase the likelihood of negative outcomes for the 16 million dementia caregivers in the U.S. (Gaugler et al 2019; Bruhn & Rebach 2014:131; Seltzer & Li 1996); further, 66 percent of caregivers cohabitate with their care recipients, more than any other form of care (Gaugler et al. 2019:31; Pinqart & Sörensen 2003), leaving them with little reprieve. Dementia care demonstrates negative effects on measures of caregiver wellness in both prevalence and severity (Roth et al. 2013; Pinqart & Sörensen 2004; Seeher 2013), and the “functional limitations and behavioral symptoms” associated with dementia (Schulz & Eden 2016:85) are noted to affect subjective well-being more than high counts of care needs (Schulz & Eden 2016:103; Pinqart & Sörensen 2004). A sense of guilt over what more can or should be done is common, if usually unwarranted (Bruhn & Rebach 2014:163; Seaman 2018).

The risks of harm from isolation, depression, burnout, sleep deprivation, and worsened health are higher for dementia caregivers than for other caregivers (Bailes et al. 2016; Bookman & Kimbrel 2011; Greenwood, Mezey, & Smith 2018), particularly for adult children and grandchildren (Nichols et al. 2011); even formal caregivers working with people

with dementia report higher levels of stress and depression than professionals caring for other conditions (Morgan et al. 2011). Burden measures often come in higher for dementia caregivers than for most other forms of care (Bailes et al. 2016; Hunt et al. 2017:18) and are sometimes customized for dementia care (reviewed in Nichols et al. 2011), but it is important to assess these figures relative to the progression of the disease, since the mid- to late-stages are associated with worse behavioral problems and a higher intensity of care overall (Hirschman & Hodgson 2018).

A strong connection between the dyad often predates informal caregiving (Bruhn & Rebach 2014:10; Sutor et al. 2016), yet caregiver assignment can be more accurately predicted by the age or condition of the prospective care recipient than by the prospective caregiver's own circumstances (Bruhn & Rebach 2014:10). Dementia caregivers describe their role as an act of love and familial commitment (Dunham & Cannon 2008), but this attitude is more pronounced in women and families of color than with men and whites (Bruhn & Rebach 2014:100-105; Shurgot & Knight 2005). Dementia caregivers appear more likely to themselves have a chronic illness or disability than other caregivers (Bruhn & Rebach 2014:153-154; Eifert et al. 2016; Wang, Robinson, & Carter-Harris 2014); however, this connection has not been explored in the literature. Forty percent of dementia caregivers report being sole caregivers (Hunt et al. 2017:23), but feelings of isolation are common among others as well (Schulz & Eden 2016:104-105).

Dementia care tends to begin with immediate family, falling to spouses first and then adult children (Gaugler et al. 2019:31; Nichols et al. 2011), although siblings and grandchildren are more involved in dementia care than other informal caregiving (Nichols et

al. 2011). Some families must change caregivers at least once, but studies are rare (Davey & Szinovacz 2008); wives, daughters, and siblings seem to be at greater risk of burnout than husbands, sons, and distant relatives (Nichols et al. 2011:29), yet spouses of persons with dementia may increase their own risk of developing dementia by giving care (Vitaliano et al. 2011). Most comparative studies have only compared dyads of one relationship type (spouses, for example) against another (adult children, often daughters), with units selected across — as opposed to within or beyond — families (Nichols et al. 2011; Schulz & Eden 2016:106; Seltzer & Li 2000).

The disparity between men and women’s prevalence as caregivers is stronger for dementia care than for other forms of care; wives, daughters, and even daughters-in-law together perform over two-thirds of all dementia care (Gaugler et al. 2019:31; Friedemann & Buckwalter 2014; Nichols et al. 2011), though not without “frustrations” over family men who expect to make decisions but not to participate in hands-on care (Dunham & Cannon 2008:48). Despite some qualitative variations in how care is performed, research into the gender of dementia caregivers has reported no significant difference in health outcomes for the care recipient.

Negative caregiver outcomes are often moderated by race or ethnicity (Angel et al. 2015). As with caregiving broadly, families of color show better resilience against negative care outcomes than white families, but also a stronger aversion to the core research concepts of “caregiving”, “care burden”, and “dementia” itself (Apesoa-Varano et al. 2015; Bruhn & Rebach 2014:102; Schulz & Eden 2016:22). Whites are the only racial group to care more

often for spouses than parents (Bruhn & Rebach 2014:105, 107), while people of color care more often than whites for other relatives and non-relatives (Nichols et al. 2011).

Marital status has a strong effect on dyad makeup from both sides. Spouses make up 12 percent of dementia care dyads; outside of spousal dyads, dementia caregivers are more likely to be married than other caregivers or the general populace (Hunt et al. 2017:35), and care recipients who are unmarried rely more heavily on siblings, grandchildren, and in-laws (Nichols et al. 2011). When caring for someone other than a spouse, however, dementia care has been found to create a greater strain on marriages than other forms of care (Schulz & Eden 2016:104). Millennial caregivers, who demonstrate the lowest marriage rates on record and are more likely to identify as LGBTQ, represent a quarter of all dementia caregivers (Flinn 2018; Gurrentz 2018).

Challenges can vary according to the age dynamic of any care dyad, and dementia exhibits strong differences by age and age difference. Dementia care seems to face more severe financial challenges when the caregiver is aged 18-35 (Flinn 2018); their careers, educations, and resilience against economic oppression may be less developed compared to both past cohorts of the same age range and older family members of the present, although there is also evidence that Millennials face greater economic hardship than any other generation since World War II (Fry 2017). Grandchild caregivers seem to be especially vulnerable to social isolation, and commonly experience both role conflict and unpreparedness (Bruhn & Rebach 2014:153; Nichols et al. 2011). Younger caregivers show a greater physical resilience against care burden, even in cases of dementia (Hunt et al. 2017:21), but Millennials and Generation Z face a ballooning prevalence of care that could

overwhelm other expectations about family and work over the life course (Cook et al. 2018; Eifert et al. 2016). Older caregivers also demonstrate financial strain but report the greatest impact to their health (Lovell & Wetherell 2011). Just over a third of dementia caregivers are themselves over 65 (Gaugler et al. 2019:31); some argue dementia care can increase the mortality of older caregivers, especially spouses (Bruhn & Rebach 2014:162-163; George & Ferraro 2016; Roth et al. 2013). Dementia caregivers of the Baby Boomer cohort report higher levels of responsibility and greater disruptions to physical and emotional health (Lovell & Wetherell 2011; Moon & Dilworth-Anderson 2015; Musich et al. 2017). Middle-aged caregivers describe not only strong emotional challenges but also the greatest conflicts of role and responsibility (Bookman & Kimbrel 2011). Caregivers supporting an elder while also parenting children under 18 are known as the “sandwich generation” (Berry et al. 2015:107) and have a high likelihood of being employed in addition to dual-care responsibilities (Hunt et al. 2015:56).

Lower income and less education attainment are each associated with better care outcomes for adult children, though researchers also associate lower income with a stronger sense of family duty (Bruhn & Rebach 2014:87); neither of these patterns has been explored deeply in the context of dementia care. Willert and Minnotte note that while research into caregiving consistently finds caregivers of color or of lower socioeconomic status to be more vulnerable to certain strains, race and income remain under-examined (2019).

Dementia research exhibits many of the research conventions discussed in the previous section, such as interviewing the caregiver while treating the care recipient as a medical case rather than examining the dyad holistically (Seaman 2018). Research into

dementia caregivers focuses on biomedical outcomes, utilization of social services, and intra-family dynamics (Davey & Szinovacz 2008; Schulz & Eden 2016:106), centering not only the pathological interpretation of dementia but also the so-called nuclear family over other care dynamics (Apesoa-Varano et al. 2015; Nichols et al. 2011); this narrow view not only excludes over a third of contemporary caregivers who are unmarried or not caring for immediate family, it also centers middle class white families in a way that is outdated, increasingly irrelevant, and methodologically specious (Eifert et al. 2016). The “cost/savings to society” paradigm is less widely utilized because dementia is seen (somewhat inaccurately) as an affliction of people who have aged out of the workforce; indeed a quarter of dementia caregivers are over age 65, and yet 21 percent of these older caregivers still work (Hunt et al. 2015:56; Hunt et al. 2017:8).

Dementia care research often happens at the local or state level, but such studies can be difficult to place in conversation with one another, or with national studies, due to methodological inconsistencies. Publicly available datasets such as the federal *National Survey of Caregivers* and NAC/AARP’s *Caregiving in the U.S.* record and report which caregiving cases center on dementia, but researchers must be careful working with the smaller samples, where convention favors homogeneous samples that hinder reliability (George & Ferraro 2016). Even studies that measure biomedical factors upon social phenomena stand accused of poor sampling (Roth et al. 2015). Perhaps the greatest weakness in dementia care research is the high number of caregiving studies that lack probability samples (Angel et al. 2015; Pinquart & Sörensen 2003, 2004; Schulz & Eden 2016:60; Werner et al. 2013), and yet go on to report statistics probabilistically (such as Wang et al. 2014). The abundance of unstandardized, by-

the-numbers statistical methods may hide the opportunity for more innovation and breadth in care study designs.

Assumptions that caregiving carries a cumulative harm for the caregiver also persists in dementia care research, which then focuses on quantifying the harm rather than complicating it (Dunham & Cannon 2008; Hermanns & Mastel-Smith 2012; Roth et al. 2015). Studies that highlight "positive aspects of caregiving" tend to make an explicit exception for dementia care (such as Roth et al. 2015; Pinquart & Sörensen 2003), although such studies exist for dementia care as well (Beard et al. 2009). Though, pathologically, dementia is an individual phenomenon and in no way contagious, the diagnosis of dementia can shake up entire families and communities. Some of the social and demographic trends for dementia caregiving follow those of caregiving in general, but others are amplified. In particular, the role of spouses and daughters is more prominent, and age differences (both between different caregivers and between a caregiver and their care recipient) have stronger impact. Caregivers of color demonstrate resilience in dementia care, but their coverage in literature is inconsistent and often lacks nuance. Specialized burden measures exist for dementia caregivers, but quantitative studies do not tend to record stages of the disorder in ways that would make the measures reliable.

As above with caregiving generally, research into dementia care appears to undervalue social aspects. Care dyads reflect the social status of the care recipient as well as the caregiver, but studies have only interrogated the influence of their biomedical condition upon the caregiving experience. Beard and Fox suggest that social research encourages “social disenfranchisement” of persons with dementia, and instead suggest a postmodern

outlook wherein the dementia is only a disability of the person's relationship to memory or time (2008:1510); this approach has tremendous implications for dementia caregivers as well, and turns questions of wellness away from biomedical fixes and toward the broader social support the care dyad receive.

### *The Dementia Care Dyad as a Social System*

According to Bruhn and Rebach, "Caregiving is a process linked to the progress of the care recipient's decline" (2014:10), with stress and stress variance that are "interactional" (156). Dementia care dyads exist in a mutually constrained tension where the actions and impacts of one affect the other, perhaps more than any other form of caregiving. At the heart of the care dyad is a constant question of prevention versus response, balancing between the interests of a thinking, feeling adult — who may not realize or accept they are sick and getting sicker — and the caregiver (and support system) that expects to outlive them. Social shifts can occur to both the caregiver and the care recipient at the same time; the less a person with dementia is capable of performing socially, the more responsibility that falls upon the caregiver to either compensate or retreat. In a meta-ethnographic review of international empirical studies and policy documents, U.K. researchers place a person with dementia at the center of a large ecosystem where interactions with the caregiver, health workers, and every level of society interact to affect their sense of personhood (Bosco et al. 2019). Similarly, Beard et al. endorse revisiting dementia as a "social process" to shift dementia toward an "experience of memory loss rather than giving prominence to biological and neuropsychiatric makers of decline" (2009:227). On the social significance of dementia, an Irish study emphasizes, "Living with dementia cannot be isolated from interactions with

others,” (Greenwood et al. 2018:44, citing Daly et al. 2012). While the contexts of these studies is beyond the scope of this thesis, their systematic viewpoints reiterate the social significance not only of dementia, but of its care and of the greater support system of its caregiver(s). Dementia care dyads already stand out in the literature; dementia care demonstrates enough qualities of a distinct social system that many care studies separate samples into two categories: dementia care and all others (see Pinquart & Sörensen 2003 for examples). This social system approach warrants further exploration.

Perhaps it is not always the case that the care receiver’s age, gender, etc., influence caregiving, but it is certainly true in dementia care, yet these social statuses are only superficial facets of a dementia care system. Without a systemic framework, we cannot, for example, uncover how the layers of socioeconomics within a care network may interact with the socioeconomic trajectory of the person with dementia; dementia care may even be ideologically sensitive: some families see dementia as either a mental illness (Stites et al. 2018) or an inevitability of aging, even though neither are true.

At the heart of this social system is not only the care recipient, but the care dyad, a “socially constructed dialectic” (Seaman 2018:64), wherein the caregiver and care recipient must navigate one another’s realities and together navigate the “real” of others (Beard et al. 2009; Bruhn & Rebach 2014:154; Hermanns & Mastel-Smith 2012). Between its fuzzy beginning (Seltzer & Li 1996) and its unavoidable end (Beard & Fox 2008), a dementia care dyad builds, sustains, and ultimately loses an inner world of their own (Hermanns & Mastel-Smith 2012; Seaman 2018). Not merely an alliance or social network (Cornwell & Schafer 2015), the depth and duration of this social entanglement fosters social consequences for

both members of the dyad and their external relationships as well (Schulz & Eden 2016:104-106). Although linear and cyclical models of dementia care exist (Bruhn & Rebach 2014:157), the trajectory of dementia symptoms is usually erratic. Caregivers may lack certainty from week to week, hour to hour, about when and how their loved one's cognitive losses will manifest (Dunham & Cannon 2008), so adaptability is critical (Bruhn & Rebach 2014:163; Roth et al. 2015). Many caregivers report worrying about letting their guard down at the wrong time (Seaman 2018), which can lead to hypervigilance, adrenal fatigue, and burnout.

#### *Social Linkages of the Dementia Care Dyad*

The responsibilities of dementia caregivers extend far beyond mere ADLs and IADLs (Pinquart & Sörensen 2004; Schulz & Eden 2016:76-77). Dementia caregivers navigate ever-shifting dynamics (Berry et al. 2015; Bruhn & Rebach 2014:163) in a way that tries to honor the present capabilities of the care recipient without exposing them to danger or emotional harm (Beard et al. 2009; Berry et al. 2015). Serving as the care recipient's primary (and sometimes only) buffer from the world, not only do caregivers decide whether or how to intervene, they also determine when intervention must escalate and processes must change (Dunham & Cannon 2008). A person with dementia may choose to pull back from social engagement (Gauthier et al. 2013), but it is more common for their social role to be withdrawn by others (Beard et al. 2009), leaving the care dyad to adapt roles and identities on their own. Bosco et al. highlight social inclusion within their model of dignity, adding that while dignity as a concept can be very individualized, “people know when they are not being treated as such” (2019).

The caregiver is generally expected to intervene if the care recipient is uncomfortable, unsafe, or unruly (Berry & Apesoa-Varano 2017), reflecting respectively the subjective feelings of the care recipient, the security of the care recipient (and possibly others), and the subjective social expectations of any other persons around. Under this dynamic, it falls to informal caregivers to "discipline and control [...] the aging body" and to researchers to reduce caregiver strain; family caregivers, particularly adult children, can see this power dynamic as a "role reversal" (Dunham & Cannon 2008:46, 52), and often describe feeling ambivalent about it (Seaman 2018). Notably, people with dementia are mistreated more often than any other elders (Schulz & Eden 2016:107; van Durme et al. 2012); they also frequently experience depression or anxiety, although studies have not yet discerned what portion of this pattern is cognitive (i.e., a symptom of dementia) as opposed to psychosocial (Beard et al. 2009).

The dementia care dyad is a power dynamic that can be uncomfortable for both members, but the erratic nature of dementia means there is no "script" available to help individual caregivers balance the particulars of safety, ability, and agency for themselves and their care recipients (Beard et al. 2009; Berry & Apesoa-Varano 2017; Gauthier et al. 2013; Seltzer & Li 1996). Berry et al. (2015) distinguish stages of caregiving by whether dyad actions are collaborative or unilateral, which is itself distinct from a spectrum of cooperation versus resistance.

The perspectives of people with dementia are often overlooked in research; over 80 percent of people with dementia live "in the community" — that is, not in any form of care facility (Hunt et al 2017:32) — and 8 percent receive no assistance (Berry & Apesoa-Varano

2017; Gaugler et al. 2019:31), yet Dunham and Cannon warn that dementia care studies “often focus on the powerlessness of the care recipient” (2008:46). Beard and Fox argue that “loss of self” for persons with dementia is “a dominant trope in America, reflecting a postmodern disorientation and skepticism regarding time-honored conceptions of the coherence and rationality of time, space, and selfhood” (2008:1510). The person experiencing cognitive loss may themselves resist the words “Alzheimer’s” or “dementia” and — fearing “non-personhood” — delay diagnosis, preferring instead to blame “memory complaints” on aging (Beard et al. 2009; Gauthier et al. 2013). While it may be easy to frame the complicated dynamics of dementia care as the caregiver's problem, Beard and Fox remind us that “the construction of an Alzheimer's identity is bi-directional, involving a pendular process of maintaining past social roles and incorporating new ones” (2008:1511).

Persons with dementia often retain a sense of their own social lives (Beard & Fox 2008); impeded more by stigma than by ability (Greenwood et al. 2018), they remain sensitive to rudeness, being ignored, and becoming isolated (Dunham & Cannon 2008). Negative reactions — not only from strangers, but even from friends and loved ones — can include talking down to the person, placing premature restrictions, or isolating them (Gauthier et al. 2013; Johnson et al. 2015; Stites et al. 2018). Elder social ties are unique, molded more by grief and health factors than employment or geography (Cornwell & Schafer 2015), and especially vulnerable to race, gender, and socioeconomic status; persons who face more and greater adversities have fewer and weaker connections than persons who do not (Cornwell & Schafer 2015). Although persons with dementia who have strong social support do not show slower cognitive decline than those with weaker support (Nichols et al.

2011), they may be less vulnerable to depression, anxiety, and other secondary consequences. Feelings of guilt, denial, or loneliness can lead a person with dementia to overcompensate — to “do what they can” (Berry et al. 2015) — however the person with dementia may have very little power to affect the burden taken on by their caregiver.

For dyads who have active families or support systems, a caregiver must not only make difficult decisions but justify them to others (Berry & Apesoa-Varano 2017; Seaman 2018); the primary caregiver is entrusted with learning the most about dementia and disentangling the person from the disease for others (Beard & Fox 2008). Tensions arise not only over what the caregiver can do but when, as many actions are warranted at one stage but not others (Berry et al. 2015). Beard and Fox (2008:1510) invoke Kitwood and Sabat to frame the unreasonable expectations held by persons without dementia as a “malignant social psychology” (also cited in Dunham & Cannon 2008; Seaman 2018), ascribing moral deficiency (cf. Mol 2002:7-13n) upon the person with dementia for having "excess disability." Caregivers or others who attempt to bring the person with dementia to "reality" are asserting a worldview that is confusing at best, placing their own needs above that of the supposed care recipient (Beard et al. 2009; Werner et al. 2013).

Dunham and Cannon emphasize the "bio-power" of this dynamic, noting, “the family caregiver is controlled by the same process of power/knowledge that disciplines the aging body with dementia” (2008:46), while Seaman (2018:68) describes the dynamic as a relationship of "non-action" that leaves caregivers feeling "tired, but not powerless." Very little scholarship examines the assumptions and power dynamics at play, although this trend is improving (Berry et al. 2015; Unson et al. 2015). Beard and Fox recommend,

“Accentuating the socio-moral necessity to care for people with dementia in ways that recognize and preserve their dignity as human beings” (2008:1511). A care recipient's resistance may have nothing to do with a caregiver's actual malfeasance, nonetheless it may be their best method for disrupting power (Dunham & Cannon 2008). A long-term, primary caregiver could be rejected at some random point, but in most cases they take on a singular prominence (Dunham & Cannon 2008); by the late stages of dementia, this bond culminates into a connection that is more instinctual than cognitive: when all others are forgotten, even the self, this (nameless, story-less, just familiar) entity makes things better, solves problems, and brings comfort.

Also overlooked in research is the extent to which the best interest of the care recipient may conflict with the best interest of the caregiver (Hermanns & Mastel-Smith 2012). Dementia caregivers may experience not only isolation from being “stuck at home” or having obligations with their time (Bruhn & Rebach 2014:109; Schulz & Eden 2016:103-106), but a functional withdrawal of family and friends (Adler & Mehta 2014; Beard et al. 2009; Greenwood et al. 2018) who are unsure how to connect with the caregiver and/or be around the care recipient. As loved ones pull away from the person with dementia, caregivers, too, are subject to severe social isolation (Dunham & Cannon 2008; Seaman 2018), which may worsen if caregivers do not find solidarity with other caregivers (Adler & Mehta 2014); what does that say about the caregiver if the care recipient becomes isolated under the unspoken assumption that the person is already “lost” — is the caregiver lost as well, or their efforts “inconsequential” (Beard & Fox 2008; Seaman 2018)? Prioritizing the comfort of others may endanger the comfort of the person with dementia; conversely,

caregivers may risk alienating limited social support if they ignore the discomforts of outsiders. Choosing between the two may exacerbate decision fatigue. To keep the person with dementia safe and comfortable, caregivers may employ misdirection or even outright lying (Berry et al. 2015; Dunham & Cannon 2008). Whatever challenges of selfhood or life course the caregiver perceives from taking time out to give care, their actual sense of a social role or sense of self is subject to being altered in the experience and its fluctuations (Beard & Fox 2008; Bruhn & Rebach 2014:158-160, 163).

Dementia caregivers who report the greatest physical impact are not those whose care recipients have the worst health, but those who began care with low social support (Bruhn & Rebach 2014:162), yet dementia caregivers report difficulties receiving adequate support (Hunt et al. 2017:3). Studies of elder social networks find that the greatest benefit comes from those who can offer material support, though wellness monitoring through regular interactions can also be beneficial (Cornwell & Schafer 2015). Families, employment, and professional support (up to and including institutionalization) all involve systemic interdependence that shifts along the care recipient's trajectory, but only professional perspectives have received systemic analyses (Schulz & Eden 2016:106).

Though limited, findings suggest that informal caregiving can offer critical support, foment family conflict, or both (Bruhn & Rebach 2014:155-160; Schulz & Eden 2016:106). Dementia caregivers may relieve pressure upon a family by taking on care and simultaneously failing to meet family expectations about their own employment, financial success, or life goals (Eifert et al. 2016; Halberstam 2005:4-10). The paradigm of family care is affected by shifts in the traditional family structure; few studies have explored the role of

divorce, step-children, and blended families in caregiving at all (Davey & Szinovacz 2008; Schulz & Eden 2016:63), let alone in regards to memory-salient dementia care. Employment has an effect on caregiving and caregiving has an effect on employment, though only negative impacts seem to receive much attention (Schulz & Eden 2016:106). There may be questions about the legitimacy of caregiving as a “career” for caregivers who leave other jobs, or suspicion over shared finances (Bruhn & Rebach 2014:153-157; Hunt et al. 2015:62). Social factors and social networks of the caregiver become intertwined, even indistinguishable, from that of the care recipient, until only the caregiver’s merged support network survives the death of the care recipient; however, not only their social support systems interrelate.

The relevant practitioners who interact with the care dyad likely shift according to the stages of the disease, although the literature does not address this. Over the course of several years, the care recipient’s general practitioner may give over to a specialist, informal support gives way to formal interventions from community or public programs, and paid in-home support becomes institutionalization. Each of these transitions and forms of support has been reviewed in literature by the relevant practitioner journals (Cornwell & Schafer 2015; Dam et al. 2016; Henning-Smith, Lahr, & Casey 2019; Parker et al. 2002), but they have not yet been aggregated to center the dyad’s perspective. At heart of many of these practitioner viewpoints is “biomedicalization” (Beard et al. 2009; Berry & Apesoa-Varano 2017; Spector et al. 2012; cf. Cockerham 2013; Mol 2002:7-13n), “an ever-complicated elaboration and dispersal of biomedical infrastructures, innovations, and discourses” (Seaman 2018:64). Foucaultian analyses of caregiver studies (such as Dunham & Cannon

2008; Roth et al. 2015; Seaman 2018) caution that many caregiver studies are merely an extension of clinical dementia research and may serve interests of the clinic (Foucault [1963]1994:117-122) without informing the interests of the populations being studied. The caregiver must serve as a conduit between the relevant system and the care recipient; this sort of case management is believed to be getting more difficult for all caregivers (Eifert et al. 2016), and for dementia caregivers may be difficult to prioritize. That said, "person-centered care" is gaining traction among intervention and medical practitioners (Whitlatch & Orsulic-Jeras 2018:S59), which may help them meet caregivers partway; Schulz and Eden (2016:220-223) endorse a model of "family-centered care" as defined by the National Quality Forum, which includes "shared decision-making," convenience, and communication as important facets.

In order to earn a place in research, informal care can no longer be regarded as an isolated topic, but one belonging to a greater social context: its power dynamics, its history in the nuclear family and biomedicine, and its epistemological quandaries do not belie but exemplify the sort of interdisciplinary topics at which social research excels. To understand informal caregivers in the U.S. is to come one step closer to understanding the people of the U.S.

### *Conclusion*

Dementia care is intensive and widespread, demonstrating complicated interactions with the gender, race, marital status, age, and income of caregivers. Support that benefits the caregiver will also benefit the care recipient; the inverse is true as well. Demographic and socioeconomic factors for both members of the dyad are known to affect dyad health and

outcomes, but their cumulative interactions are rarely explored. Peer-reviewed articles on caregiving and caregivers commonly emphasize interventions and practitioners, lacking not only a longitudinal depth but also a sociological one and reinforcing simplistic views of dementia care. Social and systemic perspectives are overlooked in care literature, particularly for high-engagement families and atypical caregivers, and even analyses of interdependence and power have yet to solidify the importance and relevance of caregiving to U.S. society.

The symptoms of dementia are experienced more socially than physically, yet biomedicalization has sidelined social inquiry. Social factors of caregiving are likely mechanisms of this system, but require deeper, more multidimensional research. The opportunity exists to develop nuance in caregiving research by centering not the caregiver or care recipient, but the mutual dyad, and to view that dyad as one system operating among many toward greater Durkheimian solidarity (George & Ferraro 2016). With a systemic outlook on dementia care dyads and their support systems, researchers can expand our understanding of informal social systems, further distinguish dementia care from other health and intimate dynamics, and close research gaps.

## THEORETICAL FRAMEWORK

While trying to reconcile tension between white feminists entrenched in academia and Black feminists who wanted "concrete action," bell hooks (1991:5) makes a case for theorization. She cautions that this work could be easily hidden or co-opted, but that the work is necessary to break down the "false dichotomy between theory and practice" in feminism and support a throughline from individuals' childhood traumas to their "healing"

group actions in the present and investing toward collective progress in the future (hooks 1991:5).

In academia today, there is no dichotomy for caregiving literature because there is so little theory being applied (Dunham & Cannon 2008). If the work of scholarship is to inform pathological outcomes or financial impacts, there is no shortage of studies that will answer these questions with statistical precision; however, if the work of scholarship is to recognize something about the human experience in how and why caregivers exist — now, not one hundred years ago nor a hundred years in the future — and if that care scholarship is at all to be healing, it needs to reconcile theory with practice, and like hooks it necessitates "engagement with collective sources" (1991:3) While a wide range of caregiver studies do exist, their theoretical grounding is just as extreme as their sample sizes: so broad that no depth can be gained or so narrow that no impact can be measured. For every study applying broad social psychology to caregivers, there is a new and distinct theory targeting caregivers, only to be forgotten after one or two studies. In between, there is nothing about how individuals engage institutions or small groups in the caregiving context. It is feasible that caregiving research could thrive if it had the structure and accountability of a theoretical canon or a discipline overseeing its rigor; as it has neither, however, care scholarship demonstrably suffers.

This review of theories makes the case that care research is a social phenomenon and could be implanted in sociology without slowing from existing research trajectories. Multi-layer frameworks require versatile theories, but with sociological designs scholars can expand care research in every direction. As the power dynamics of dementia care specifically are

explored, the need for a critical perspective emerges, with the post-Foucault model of queer subjectivity (Halberstam 2005) and the multi-contextual model of intersectionality (Crenshaw 1991, 1993) selected for the present study.

### *Curing vs. Caring*

Social inquiries must confront the question of positivism: whether truths uncovered are fully knowable or probabilistic at best (Moradi & Grzanka 2017). Even so-called “hard” sciences now make room for post-positivistic stances, but the divide itself is still quite binary; one cannot study planets in the same way one studies quanta because the physics function differently, so scholars must specify their scope. When social scientists design a study, that study usually takes either a quantitative or a qualitative stance. These viewpoints are specialized to extreme contexts of inquiry and only rarely and with great care can qualitative and quantitative methods be applied to the same subject at the same time. As Adler and Mehta assert, “in the real world things are ‘connected’” (2014:8). Outside of mixed methods, which are rare and cumbersome, it is theory that helps connect the different stances and show their relevance to one another. Sociology explicitly includes all levels of social engagement and has set many precedents for linking different contexts to one another, making it ideal for developing a systematic read of caregivers. We see that caregiving research favors either the biomedical/demographic stance (quantitative) or the narrow, situational stance (qualitative), but developing their relationship to one another (and to greater society) requires theories and frameworks that can bridge the micro and the macro. What is needed is a theoretical approach that can connect many layers at once from the national demographics to the personal engagement of the care dyad.

The relationship between caregiving and sociology need not be one-way. In making their case for aging research, George and Ferraro summarize the social sciences as asking, “what mechanisms convince societal members to create and sustain societies, even when those mechanisms require members to sacrifice some of their own resources, gains, and autonomy?” (2015:np). This framing perfectly describes the impact caregiving research can offer sociology, and may even lead to new, non-bureaucratic answers to Durkheim's fundamental sociological question of solidarity. George and Ferraro go on to state, “no matter how much structural arrangements appear to differ across societies, the functions they serve are the same” (2015:np). This invites the sort of multi-modal frameworks where sociology works best.

The review above demonstrates that care research tends to polarize toward the macro- and micro-levels, with little development in-between, nor momentum to fill the gaps (George & Ferraro 2016). This pattern marginalizes caregiving as a phenomenon that is studied as solely pathological — or worse, as a solely logistical response to pathology (Schulz & Eden 2016:163). Apesoa-Varano, Barker, and Hinton refer to this divide as “curing” versus “caring” (2011), and Seaman indicates a further discernment is occurring between “caring for” and “caring about” (2018:65). Here, “curing” is broad shorthand for the biomedical model, a conquering of bodies rooted in nineteenth-century bureaucracy (Foucault [1963]1994:64-82; Lock 2002:33), which necessitates a certain approach to categorizing, studying, and treating that which is errant. Theoretical reflections on how biomedicine is enacted find that the emphasis remains binaristic — sick or not sick (Mol 2002:7-13n) — without looking at patients holistically or socially (Cockerham 2013). From

this logistical (curing, or curing-adjacent, since no cure exists for dementia) outlook, it may make sense to honor life by prolonging it, increasing a prominent quantitative measure, and therefore to assess caregivers by their contribution to prolongment and measure interventions by their measurable improvements to caregivers' measured outcomes. In other words, there is a lot of measuring and very little attention to care as a social or systemic process. A logistical approach is direct and simple, finding facts on the ground as they are. There is no need to challenge statistical conventions, nor look beyond the most numerous/visible/normative populations for impact or significance — count the big groups and delimit the "others." A logistical approach leaves no room, nor has any need, for disciplinary tradition or theoretical framework, but neither does it offer any indication what is to be measured when life cannot be prolonged, as is currently the case for persons with dementia.

And yet, even a logistical viewpoint calls for better data than purely quantitative studies have been able to provide. Caregiving scholarship often suffers from inconsistent rigor and unresolved contradictions, leaving very few studies that can be compared to one another directly (Davey & Szinovacz 2008; Pinquart & Sörensen 2003; Schulz & Eden 2016:45). Even Medical Sociology — rooted as the practitioner's ally (Cockerham & Ritchey 1997; Mol 2002:7-13n) — has advanced beyond mere logistics to recognize the need for studies of patients' social factors, because disparities effect a measurable difference upon wellness (Cockerham 2013).

Caregiving scholarship, on the other hand, often fails to challenge methodological or even popular assumptions about caregiving. Researchers echo communities in viewing

caregiving as an isolated, biomedical, aging-related, and inherently negative phenomenon to be fixed rather than a collective, social, multi-faceted, and mixed/positive phenomenon to be understood and enhanced (George & Ferraro 2016; Roth et al. 2015). Studies often measure outcomes for the care recipient or for the caregiver but not both (Schulz & Eden 2016:106). While macro-level research tends to compartmentalize caregivers into binary boxes (formal/informal, primary/secondary, employed/not employed), the broader implications of 16 million people a year dedicating a significant portion of their lives to something other than income or procreation are rarely explored. With each caregiving study serving a different research tradition, gaps and inequalities can always be someone else's problem. This trajectory leaves not one rich and intricate canon to be organized and developed, but several pools of oppositional chaos; here, studies of high and low quality alike receive very little attention or follow-up because they have no way to stand out. Discomfort on the part of would-be research participants is seen as a failing of the recruit, not of the research itself (Bruhn & Rebach 2014:110). Further, biomedical inquiries might discern that social support helps improve outcomes for the care dyad, but examining the qualities of that support falls outside their research scope.

Both logistical and social considerations matter in caregiving. Unfortunately, the tension between “medical” and “social” priorities is not even new in caregiving: a 1980 article from the Rand Corporation warns that discussions over long-term care carry the same tension, and that favoring the biomedical perspective alone creates a setback for social policy (Kane & Kane 1980). Invoking “heroic medical measures” and disability, the authors specify, “The very permanence and intractability of these problems argue for societal provisions to

protect the elderly from a permanent patient role for decades before their death” (Kane & Kane 1980:241), and yet this very phenomenon is a growing reality for U.S. elders (Eifert et al. 2016). Forty years later and still without a firm methodology or design structure, caregiving research remains disconnected from social and economic topics, even from its own context — and it shows little sign of dramatically improving the lives of caregivers. Many social inequalities continue or are even exacerbated in a caregiving context. Caregiving continues, research continues, but they do not connect.

Caregiving research has some footing in several disciplines — of which nursing, itself sometimes seen as an elevated version of caregiving, may be the best fit (Bruhn & Rebach 2014:22) — and even within social theory, but efforts to unify all facets of caregiving are rare. In 2014, Bruhn and Rebach published *The Sociology of Caregiving*, a textbook attempting to pull together many of the disparate research threads. While it is a useful compilation of research findings up to that point, it suffers many of the logistical limitations discussed above: efforts to place caregiving in a global context rely on numbers and scale, with significantly less attention to the lived experiences of caregivers or the interconnectedness of layers. The authors rightly point out how social inequalities interact with care dynamics (2014:79-119), but only in the process of attempting to organize the chaos — not to apply it forward and further understanding. Continuing the pitfall of serving pathological interests through simplistic designs, many facts and figures are presented without commentary. No efforts are made to reconcile disparate methods or address academic distribution of care topics (in fact, while there are chapters devoted to policy and social media, no chapter or segment reviews caregiving research methodology). Perhaps the weakness of this text is a

continuation of the sidelining of caregiving as only a tangent to social problems, not a social problem or social system in its own right, but more likely it is simply trying to do too much with a subject that lacks cohesion. Caregivers are not a monolith (Cook et al. 2018; Montgomery & Kosloski 2013; Morgan et al. 2011), and treating all care dynamics the same is perhaps a better exercise for research on altruism or anthropology (Roth et al. 2015; Seaman 2018) than for sociology. To see the systematic-social, it is necessary to recognize that disease itself can be social (Beard et al. 2009), that dyads interact with and outside of families and larger support networks (Bosco et al. 2019), and that caregiving looks dramatically different for a broken leg than it does for dementia. Before a holistic viewpoint can be developed, perhaps fitting care experiences into a spectrum or small matrix, some of the most distinct care dynamics must be outlined more clearly (Brodaty & Donkin 2009). This study takes the first step by separating dementia care and deepening its quantitative and literary context.

To keep caregiving on the periphery of biomedical research is to overlook the inherent discord of priorities; the goal of medicine — to prolong life — is secondary at best to the dementia caregiver, while quality of life is secondary at best to models of pathological treatment (Foucault [1963]1994:117-122). Previous attempts to theorize about caregiving have come from the life course perspective, feminist ethics of care, and social role theory (though not other approaches from Sociological Social Psychology), but none has succeeded in attaching caregiving as an important component of theorization, nor as a niche worthy of ongoing study. Life course perspectives tend to reiterate that, aside from parenting, some level of caregiving is associated with old age (Bruhn & Rebach 2014:41-42), but this

overlooks demographic shifts and cultural contexts — again, caregiving as we know it exists in this time and place for a reason. Scholars of ethics of care work to elevate the study of compassion and qualitative judgment to an academic level, but struggle to disentangle the construct from gender essentialist implications and sharpen the distinction between literal and metaphorical “care” (Barnes & Brannelly 2008; Jordan 2020). Role theorists look to discrepancies (which affect measures of caregiver burden) rather than consistencies (Bruhn & Rebach 2014:8-9, 157; Savundranayagum & Montgomery 2010). Other theories that have gained traction include predicting caregiver outcomes with the stress-process model (Moon & Dilworth-Anderson 2015; Nichols et al. 2011) and development of a caregiver identity theory (Friedemann & Buckwalter 2014; Montgomery & Kosloski 2013), but they are designed once again to support interventions, to meet curing (or curing-adjacent) priorities. These findings tend to speak to the role of the caregiver within a family or a biomedical context, but not within a community or society at large.

To break away from the curing vs. caring tension requires a theoretical framework that can be applied across the macro/micro disconnect, that is just as concerned with large-scale disparities as it is with individual outcomes, and ideally that also considers the agency and quality of life of the person with dementia (Berry et al. 2015). Having rejected the concept of victory over a disease that cannot yet be stopped, this study approaches Foucaultian/post-structural priorities (i.e., that research concerns cannot be further addressed without decontextualizing and recontextualizing the social powers that led to this point). While post-structuralism is not inherently anti-intervention, it does center alternative

questions about why and how current intervention models even exist (i.e., in whose service?). The only theories that meet all these criteria are critical theories.

*Critical Theories: Queer Subjectivity and Intersectionality*

By applying a critical approach, we allow for the possibility that caregivers' social experiences may run deeper than a mere lack of social support. It is not enough that caregivers are doing too much work or that they feel isolated doing so; they are being systematically excluded from societal relevance by a society that has no place for them and fails to contextualize their endeavors beyond economic measures. Though individual caregivers may be regarded highly for their contributions, caregiving is not a common nor comfortable topic in the U.S. because it is incongruous with expectations and values. Fraser invokes capitalistic roots in a growing "crisis of care" and how the familial care gap is being filled for the Global North with immigrants from the Global South (2016:112; see also Glenn 2010:181; Halberstam 2005:19; Scales et al. 2020). Not only are existing inequalities being exacerbated by the work of caregiving, but new ones are being created.

Seaman also points out that in the biomedicalization model, the future has become "the site where solutions to our medical ills lie," and cautions that all dementia care work could be invalidated if/when a cure is found (2018). The sense of time as experienced by caregivers is a good example of just how far removed from "everyday" society many caregivers are. In a series of 2011 blog posts for National Public Radio, astrophysicist Adam Frank approaches social science in discussing how one's relationship with time is "particular to our culture and our history" (2011a). Frank blames contemporary "time-logic" on industrial concepts of efficiency, linking it to contemporary challenges as climate change,

over-consumption, and precarious economies (2011c). Frank further postulates that, “As individuals, the desire to build a new [time-logic] springs from our deeply felt need to reclaim *value* and *balance* in our lives” (2011a:np, emphasis in original). Essentially, what Frank asserts is that time is social, and in doing so, he implies that anyone who does not participate in the (economic, work-centered, mainstream) time — what he calls a “time-bender” (2011b) — is anti-social.

Queer theories also address anti-social relationships with time. Halberstam suggests that alongside the centering of work-time, there is also a “reproductive temporality” and that deviation — any deviation — constitutes “queer time” (2005:4-6; cf. George & Ferraro 2016). Because there is no room in the normative society for anyone who “leaves the temporal frames of bourgeois reproduction and family, longevity, risk/safety, and inheritance,” such a person is othered; temporally, they are “queer” irrespective of their sexual or gender identity (Halberstam 2005:6; Halberstam is here deploying “queer” as a label of vague/unsortable and transgressive outsider-dom). Queer time might especially fit someone who exits a traditional (employed, procreative) life course to take care of someone with neither reproductive nor income potential; unlike marginalized persons or directly experienced hardships, a caregiver has some level of choice in the matter (even if the choice is between becoming a caregiver or letting a loved one decline alone and unsupervised).

It turns out there is a lot separating caregivers from non-caregivers. Writing specifically about dementia care, Beard et al. remind us that efforts to “fix” persons with dementia are “predicated on the superiority of present-time orientation, where the goal is to restore ‘reality’” (2009:228). The authors discourage “enforcing our cognitive reality by

letting go of normative expectations and ‘joining’ people with dementia in their worlds” (Beard et al. 2009:228), and in doing so suggest there may be nothing wrong with not fitting the common time-logic at all. To be clear, most caregivers struggle with their care recipients’ altered reality and probably would retain a role in the dominant time-logic, but it is not the person with dementia who isolates them for the deviation; the assertion of a single and universal “way” of being in the world means that those existing in queer time — whether or not by choice — must be marginalized, lest the practice spread further (Halberstam 2005:10-12, cf. Montgomery & Kosloski 2013; Schulz & Eden 2016:105). This is how you get queer subjectivity.

Halberstam also introduces “queer time” as another facet of queer subjectivity, describing queer space as “new understandings of space enabled by the production of queer counterpublics” (2005:6). Queer spaces may be rooted in non-heteronormative sexuality, but what is created there is not just for LGBTQ people; it certainly is not for everyone (there is still a normative, cisheterocapitalist reproduction cycle out there, humming along, from which queer subjects are discarded), but it might be for anyone. Queer subjectivity, then, is queering the definition of “queer” itself (Hall 2003).

Recall that dementia caregivers live as much or more in the world of their care recipient as their own; their understandings of space and time become fluid, not entirely their own, and that others’ positivistic constructs of reality are irrelevant at best (harmful at worst). Whether or not an individual caregiver applies some definition of “queerness” to their life, there is room for their counterpublic in queer space and time, themselves forged and scarred by the AIDS crisis, its victims, and its caregivers (Halberstam 2005:2); witnesses

to dementia in particular are familiar with a “constantly diminishing future.” Queer subjectivity may apply to any caregiving situation, but especially to those who delay or sacrifice normative life courses that were otherwise available. As a research framework (which Halberstam uses elsewhere in the same book to develop counternormative archives for Brandon Teena and other queer narratives that had been altered and accepted in normative media), it says first and foremost that there is valuable information in non-normative experiences; these experiences are not always a matter of failings or of limited opportunities (although caregivers and their prior employment prospects comprise a research gap waiting to be filled!), but of choices that are not recognized. Queer subjectivity is taking the opportunity to give illicit recognition, to see the unseen, and perhaps to allow them to tell their own stories (Seaman 2018).

Because queer subjectivity is posited as more of an interpretive stance than a research orientation, a clear methodology is vital to its application. Scholars who call for more “specialized categories of caregivers” (Brodaty & Donkin 2009:224) specifically link this need to growing evidence of health inequality (Cook et al. 2018). Both quantitative and qualitative approaches risk repeating societal erasure and diminish academic rigor when they look at gender, race, and class as separate phenomena from health status, quality of life, or caregiving outcomes. Developing such categories would require studies to both identify significant patterns across large surveys of caregivers and offer context for the patterns as measured. Public datasets allow and invite secondary inquiry to clarify these patterns, but giving them context will require a theoretical foundation that is both sensitive to the variety of care dyads and recognizes their origins in broader hegemony. Fortunately, studies are

calling for more intersectional perspectives in health and aging research (Evans 2019; Ferrer et al. 2017; Gkiouleka et al. 2018; Hankivsky 2012; Richardson & Brown 2016).

Intersectionality examines the complicated, often material, outcomes for persons who face multiple forms of systemic oppression at the same time (Crenshaw 1991; Hancock 2016:12). In the simplest terms, persons who face both racism and sexism in the workplace demonstrate lower wages and fewer promotions than those who face racism or sexism alone (Crenshaw 1991), but these forces also have implications upon activism, politics, and social science (Crenshaw 1993; Hancock 2016:7-11; Moradi & Grzanka 2017). Intersectionality asserts that not only is it significant to recognize when and how these disparities amplify one another, but that systems of redress refusing to acknowledge more than one form of discrimination at a time are themselves sources of systemic oppression (Crenshaw 1991, 1993). Intersectionality offers an inversion of social stratification, the positivistic sociological theories collectively asserting that we can come to understand macro-social power dynamics, if only through ever-more precise (and complex) matrixes of separation (Grusky & Weisshaar 2014:4-15, 45, see also Tumin 37 in the same volume; Wright 2005:12-21, 26, see also Breen 41 in the same volume); instead, intersectionality asserts that to comprehend the magnitude of a person's "total" marginalization, you do not divide the forces against them and add them up, but combine them and pay attention to their cumulative, qualitative impact (Crenshaw 1991, 1993; Moradi & Grzanka 2017).

Intersectionality is the culmination of a hundred years of Black feminist thought, seeded by the time Anna Julia Cooper wrote in 1892 of the "unique position" of Black women as not merely Black and not merely women, but "confronted by both a woman

question and a race problem” (Guy-Sheftall 1995:45; cf. Crenshaw 1991). The Combahee River Collective expanded this sentiment in 1977, stating, “We [...] find it difficult to separate race from class from sex oppression because in our lives they are most often experienced simultaneously” (Guy-Sheftall 1995:234; cf. Moradi & Grzanka 2017). Kimberlé Williams Crenshaw named intersectionality and cemented its academic stature in two law articles in the early 1990s, situating the need for multifaceted frameworks against oversimplified legal battles over equal pay and censorship (1991, 1993). While its applications comprise any situation where social marginalizations do not merely accumulate but create unique and complicated disparities, intersectionality is founded and defended through the tradition of Black feminists of the U.S.

The face value for quantitative applications may seem low because intersectionality has developed as an interpretive (Hancock 2016:12-13) practice of critical resistance against discrimination, harmful binaries, and having to compromise to pursue recourse and identity. Bringing this interpretive framework is not a simple matter of mathematically adding together several disparities and calculating their cumulative harm, and theorists fearing dilution and appropriation now push back against scholars who conflate intersectionality with any study invoking multi-layered identities (Moradi & Grzanka 2017). What matters is not whether there is a mathematical approach, but where the math is rooted. Material differences do exist, they can be traced to social and systemic discrimination, and they can be calculated for a specific population, but this process must originate from the population itself (Moradi & Grzanka 2017). Intersectionality does not resist quantitative inquiry, only the quantitative predilection for rigid standardization. Oppressive forces are in a constant

state of flux (indeed, perhaps time — or Queer Time — should be added to the intersectionality toolbox, but this question is outside the scope of the present study), so no scholar can ever say they have identified the textbook formula for intersectional enumeration for all caregivers; we can only say that we have observed certain patterns within a particular population at a particular time and, from there, calculate the (socio-)economic impact.

The call for intersectional analyses to hone and apply quantitative methods is growing (Bauer & Scheim 2019), including in health contexts (Green, Evans, & Subramanian 2017; Hankivsky 2012; Richman & Zucker 2019; Warner & Brown 2011). Combining intersectionality and statistical analysis will not only improve the quality of statistical methods (by, for example, contextualizing systems of oppression in interaction effects), but also continue the advance of feminist inquiry beyond theory and ontology (Scott & Siltanen 2017). Importantly, as argued by Ange-Marie Hancock in her Black-woman-led review of intersectional topics, “intersectionality-like thinking about how power is relationally constituted predates and anticipates Michel Foucault’s well-known arguments about power” (2016:164; cf. Foucault [1963]1994:99-100). Studies that look at, for example, race and gender together can improve the present but also elevate the history (individual and collective) of participants (Richardson & Brown 2016), which will also expand other critical standpoints.

Applying intersectional approaches to caregivers is not only helpful but necessary, because “unique characteristics of various racial and ethnic minorities interact with the challenges common to all [care situations] and result in substantially different outcomes” (Angel et al. 2015). When scholars treat caregiving as a gendered phenomenon, they obscure

the ways multiple marginalizations place the disadvantaged caring for the advantaged; in the middle class, it may be women caring for men, but in long-term care facilities it is the working class caring for the middle class; in cities it is the less educated caring for the highly educated; in many states, it is people of color caring for whites; and across the country it is often the immigrant caring for the citizen (Glenn 2010:181; Scales et al. 2020). These oppressive dynamics do not operate separately, but in constant interaction with one another, rooted in many of the same assumptions about a positivistic, right or wrong world; this is why intersectionality must remain interpretive and contextual, and why caregiving must be seen as more than just a gendered phenomenon.

### *Conclusion*

This section has reviewed some of the theoretical frameworks that have previously been applied to dementia care and caregiving research at large and detailed the challenges that have emerged. In promoting a sociological research stance toward dementia caregiving, this study moves away from interventionist perspectives that have little interest in the support systems of caregivers and has faltered in the face of health inequalities. Critical theories are suggested as an alternative that can meet the needs of dementia caregivers, their care recipients, and practitioners of all levels. Halberstam's queer subjectivity and intersectionality are selected to advance the current analysis through inquiry of how othering may occur against and between informal dementia caregivers.

### HYPOTHESES

This study examines the effect of intersecting social marginalizations upon dementia caregivers, themselves a distinct (potentially othered) subset among informal caregivers. An

existing quantitative dataset is utilized to demonstrate that critical theories can be applied to data collected in a straightforward, positivistic manner. The following three hypotheses will test whether social disparities demonstrate a significant impact upon dementia caregivers; to a lesser extent, they will also explore the potential for sub-categorizing dementia caregivers according to advantages and disadvantages in their care circumstances.

*H<sub>1</sub>: The age of dementia onset among care recipients varies by race.* This hypothesis places a pathological benchmark in the context of social marginalization. Generally, dementia is considered “early onset” if it is diagnosed before age 65, but a racial disparity that favors whites could indicate that people of color are being ignored or systematically excluded in the development of pathological benchmarks. This hypothesis will be tested through cross-tabulation and chi-squared and its relevance explored.

*H<sub>2</sub>: Dementia caregivers with normative characteristics will demonstrate less physical strain than non-normative caregivers.* This hypothesis tests whether reports of low physical strain are significantly concentrated in caregivers whose demographics are most common or average. Physical strain tends to be one of the lower burden measures among dementia caregivers; however, it is not often stratified by social factors. Factored in a multivariate regression model, these social indicators may demonstrate that normative caregivers have an outsized influence on means, obscuring the physical strain reported by non-normative caregivers, or those othered for having few of the following normative traits: white, woman, over 50, higher income, not employed, caring for a parent.

*H<sub>3</sub>: Dementia caregivers with higher social marginalization will demonstrate a higher ADL index than other caregivers.* This hypothesis tests whether the ADL index measures significantly

higher among caregivers who face more intersections of social adversity — in other words, a measure of care intensity will be assessed to determine whether caregivers who are othered by society are othered amongst caregivers. ADLs are often counted as an “objective” measure of care burden, but this hypothesis asserts that care dyads who face historical and ongoing disadvantages will see health and care disparities reflected in their care challenges. Multivariate linear regression will be employed to identify a significant concentration of socially marginalized caregivers and compare their ADL indexes against caregivers with the fewest marginalized traits: person of color, woman, lower income, less education, employed, solo, and sandwich generation.

## CHAPTER III

### DATA AND METHODS

This chapter introduces the secondary dataset to be employed and a description of care variables utilized. Statistical methods (correlation matrixes and multivariate regression) are discussed and limitations of the study are discussed.

#### DATA

This study utilizes *Caregiving in the U.S.*, a periodic, public interest survey of adult caregivers that includes both objective and subjective items about the care dyad. Four waves of this dataset exist (1997, 2003, 2009, and 2015, although 2015 employs a new methodology) and are available to the public for download without registration. A new wave is being released in 2020. Data related to dyad demographics, characteristics, self-reported stress, and an index of total ADLs were examined within the 2015 wave (conducted in late 2014) via SPSS 25.

#### *Sample*

From a random online sample of 7,660 nationwide adults, 1,248 online surveys were completed by adults who had given care to some other adult in the prior 12 months (NAC/AARP 2015). Oversamples are not included as they fall outside the scope of this study. The sample is weighted according to the specifications recommended by the dataset's methodology and codebook, resulting in a dementia caregiver population of  $N = 259$ .

## VARIABLES

Cases have been restricted to dementia caregivers who answered all necessary items for the dependent variables. This section describes the variables as originally coded and initial modifications made therefrom; invalid responses (*Not Sure/Don't Know* or *Refused*) are omitted.

### *Dependent Variables*

For dependent variables, this study utilizes one indicator of dementia scope and three indicators (one objective and two subjective) of care burden. For the scope of dementia, age of onset estimates when the care recipient began to receive care for dementia; this interval-ratio variable, measured in years, was calculated by subtracting the survey's item for duration of care from the age of the care recipient. This calculation does not recognize potential changes in caregivers or situations where the care recipient previously received care for something other than dementia, yet it is the closest we can get with the available data to age of diagnosis or visible onset; a dichotomous version tracks those who are estimated to have experienced early onset (*Age 65 or Over* = 0, *Age 18-64* = 1).

For subjective caregiver burden, two survey questions record physical strain or emotional stress from caregiving as reported by caregivers. For both 5-level scales, the lowest item (recorded as 1) was *Not a strain at all* (Physical Strain) or *Not at all stressful* (Emotional Stress) and the highest item (recorded as 5) was *very much a strain* or *very stressful*; the available responses approximate respondent attitudes but cannot be quantified rationally, so they are ordinal variables.

The remaining dependent variable is an index of ADLs as counted by NAC/AARP, based on cumulative (recorded as *No* = 1 and *Yes* = 1, but here modified so that *No* = 0, *Yes* = 1) responses to the following items:

- Getting in and out of beds and chairs
- Getting dressed
- Getting to and from the toilet
- Bathing or showering
- By dealing with incontinence or diapers
- By feeding him or her

This dataset records a total of six ADLs, so the range for ADL count is 0-6; the higher the count, the more types of daily support the caregiver delivers. Since the severity of ADLs are not quantifiable as regular intervals, this index constitutes an ordinal variable.

Note here that other studies tend to combine the mobility measures — *getting in and out of beds and chairs* and *getting to and from the toilet* — into one item, resulting in only five total ADLs; NAC and AARP do not explain this methodological decision, but do report a 16-point difference between the mobility measures as separated (Hunt et al. 2015:40).

**Table 1.** Dependent Variables Used in Analysis of Social Aspects of Dementia Care Dyads, 2015 (NAC/AARP)

Variable	Mean	Std. Dev.	Skew	<i>t</i>
Self-Reported Physical Strain (5-Level)	1.7364	1.26160	.218	22.161
Self-Reported Emotional Strain (5-Level)	2.4525	1.17694	-.305	33.553
ADL Count (0-6)	2.1470	2.13535	.573	16.189
Age of Onset (Years)	72.3724	16.58402	-1.583	70.267

#### *Independent Variables*

The following dyad characteristics serve as independent variables: relationship, caregiver age, caregiver primary status, and caregiver employment status. Relationship is recorded as a 36-item categorical variable referring to the relationship between the dyad —

whether they are partners (coded as 4: *Companion/Partner*, 20: *Spouse*, or 36: *Same-Sex Partner*), parent/child (coded as 6: *Father*, 7: *Father-in-Law*, 13: *Mother*, or 14: *Mother-in-Law*), some other type of relative, or not related (coded as 24: *Friend*, 25: *Guardianee*, 26: *Neighbor*, or 27: *Other Non-relative*) — based on responses to the survey question “Who are you caring/did you care for?” Three dyad relationships (Family, Partnered, and Parent) are recoded dichotomously (*No* = 0, *Yes* = 1) as needed. Primary is a dichotomous variable initially calculated ordinally (*Sole Caregiver* = 1, *Primary but not sole* = 2, *Someone else is primary* = 3, and *Shared equally* = 4) that reports whether the respondent served as primary caregiver (*No* = 0, *Yes* = 1); this study also created a dichotomous (*No* = 0, *Yes* = 1) variable for solo caregivers (all solo caregivers are primaries, but not all primaries are solo), and inverted solo to report whether a caregiver has Unpaid (informal) Support (*No* = 0, *Yes* = 1). Employment is a dichotomous variable (initially recorded 1 = *Employed*, 2 = *Not Employed*, recoded *No* = 0, *Yes* = 1) reporting whether the caregiver says they were employed and caregiving simultaneously at any time during the previous year.

#### *Intervening Variables*

The following caregiver demographics serve as intervening variables: gender, race, education attainment, household income, and caregiver age. As women are central to two of the hypotheses, gender is here discussed as a dichotomous variable for woman (initially coded as *Male* = 1, *Female* = 2, here recoded so that *Man* = 0 and *Woman* = 1; see Introduction for notes on terms of inclusion). Race was recorded across multiple survey questions and merged in data collection as a 5-item categorical variable (*White* = 1, *Black* = 2, *Asian* = 3, *Other* = 4, and *Hispanic* = 5); for this analysis, two dichotomous variables report

when a caregiver is white (*Person of Color* = 0, *White* = 1) or a person of color (*White* = 0, *Person of Color* = 1), and a third dichotomous variable reports on Black and non-Black people of color (*Non-Black POC* = 0, *Black* = 1). Education attainment depicts highest education attainment (initially coded ordinally as *Less than High School* = 1, *High School grad/GED* = 2, *Some College* = 3, *Technical School* = 4, *College grad* = 5, *Graduate school/Grad work* = 7) and is here recoded dichotomously based on whether the caregiver has attained some certification beyond high school diploma (*High School Diploma or Less* = 0, *Trade/College/Graduate-level Certification* = 1); as will be discussed in the next chapter, another dichotomous variable was created for caregivers reporting the least education (*High School Diploma or Beyond* = 0, *No Diploma* = 1). Household income (in dollars, initially merged from several questions into the following near-ordinal categories: *Under 15000* = 1, *15000-29999* = 2, *30000-49999* = 3, *50000-74999* = 4, *75000-99999* = 5, *100000 or more* = 6; codes 9 and 10 report incomes that were, respectively, *less than* or *more than 50000* but otherwise unspecified) is presented here dichotomously (*Less than 50000* = 0, *50000 or More* = 1); note that the U.S. national average household income for 2014 was \$53,657 (DeNavas-Walt & Proctor 2015). Caregiver age was recorded in years as an interval-ratio variable, but is here presented dichotomously (*Ages 50+* = 0, *18-49* = 1); an inversion of this variable (*Ages 18-49* = 0, *50+* = 1) is also utilized for older caregiver.

## DATA ANALYSIS

### *Bivariate Correlations*

Cross-tabulation is a specific type of correlation matrix specialized for unmatched levels of measurement across only a few categories. Cross-tabulation measures the

significance — but not the strength — of superficial relationships by measuring correlation between all categories within the variables compared. Because this method involves a correlation matrix that subdivides into smaller batches, some variable categories have been merged or omitted to fewer levels per statistical convention.  $H_1$  is tested utilizing a controlled cross-tabulation.

### *Multivariate Linear Regressions*

Multivariate linear regression is a statistical technique that determines whether a dependent variable can be predicted by some combination of independent and intervening variables. Statistically significant regression models report the strength and direction of a predicted relationship, as well as its significance; errors between expected and actual outcomes are minimized by squaring and adding them together and letting the lowest possible total determine the effectiveness of the regression (this technique is called ordinary least squares). These interactions are relevant to intersectional concepts because models of co-occurring variables can demonstrate an impact upon a dependent variable that is more (or more complicated) than the sum of their individual interactions (Evans 2019:95); such models can be merged into a single variable (called an interaction effect) for further analysis. By exploring data in this manner, complex patterns become predictions, explaining variance within a specific population (such as subsets of dementia caregivers).

Multivariate linear regression measures the relationship between interval-ratio variables. Dichotomous variables, if prepared appropriately, can also undergo regression (with each other or with interval-ratio variables) as dummy variables. A dummy variable must be stated strictly in terms of a single category (i.e., “dummy” and “not-dummy”), with

the largest category conventionally serving as referent (“not-dummy”). Regressions can theoretically consider many variables at once, but when significance is equal, a simple solution is preferred over an exhaustive one.

The two remaining hypotheses,  $H_2$  and  $H_3$ , are tested via multivariate linear regression in Chapter 4. Under guidance from the theoretical framework, each hypothesis will test three models to predict variance with the variables introduced here. Models will include a set of variables as predictors, ranging between two and nine each, and the significance of the optimal combination will test the hypothesis. These inquiries seek to identify niches within dementia care dyads where social disparities are most evident.

## CHAPTER IV

### RESULTS

This chapter reviews the results of the data analysis. Descriptive analysis for primary variables is presented, followed by discussion of how findings impact the hypotheses.

#### DESCRIPTIVE STATISTICS

The social aspects of dementia care are numerous and complex. Table 2 shows the distribution of demographics and care traits among dementia caregivers and confirms much of what NAC/AARP and NAC/Alzheimer's Association publications (Hunt et al. 2015; Hunt et al. 2017) have disclosed about this sample. While the distribution of race closely resembles the make-up of the United States, caregiver age skews in favor of older caregivers and gender demonstrates a clear skew in favor of women (although men are more represented in dementia care than in caregiving at large). Education is split nearly down the middle; income skews in favor of households making more than \$50,000 a year, though at this level we cannot say it is necessarily by much.

Relationships show to be an important factor in dementia care. Over half of dementia care is between a parent (or parent-in-law) and adult child, with care of partners representing another quarter. More caregivers support a person who is not related to them than care for siblings, grandparents, and other relatives combined. Of dementia caregivers, one in four has a child under 18 living with them (i.e., they constitute part of a sandwich generation).

**Table 2.** Independent and Intervening Variables Used in Analysis of Social Aspects of Dementia Care Dyads, 2015 (NAC/AARP)

Variable	Category (n)	Sub-Category (n or mean)	%	Std. Dev.	Skew
Gender	Women (150)		57.8	.49480	-.319
	Men (109)		42.2	.49480	.319
Race	White (172)		66.4	.47325	-.698
	Person of Color (87)		33.6	.47325	.698
		Black (35)	13.4	.49239 <sup>a</sup>	.423 <sup>a</sup>
		Non-Black POC (52)	20.2	.49239 <sup>a</sup>	-.423 <sup>a</sup>
Education	HS or Less (134)		51.7	.50069	-.067
		No HS Degree (18)	7.0	.25609	3.382
Income	Certified beyond HS (125)		48.3	.50069	.067
	Above 50K (149)		57.6	.49515	-.309
Caregiver Age	Below 50K (110)		42.4	.49515	.309
	Over 50 (168)		64.8	.47865	-.621
Relationship	18-49 (91)		35.2	.47865	.621
	Family (228)		87.8	.32795	-2.323
		Parent-Child (138)	53.2	.49997	-.127
		Partnered (63)	24.5	.43076	1.194
		Other Relative (27)	10.2	.58025	-.009
	Non-Family		12.2	.32795	2.323
Employment	Sandwich		26.2	.44051	1.090
	Employed (161)		62.2	.48584	-.506
Scope	Not Employed (98)		37.9	.48584	.506
	Primary (161)		58.1	.49430	-.332
		Solo (98)	37.7	.48553	.511
	Unpaid (162)		62.3	.48553	-.511
Age of Care Recipient (76.6)				14.54000	-1.179
	at Onset (est.) (72.4)			16.58402	-1.583
	Care before 65		22.6	.41873	1.321

<sup>a</sup> calculated within parent category only

Employment is also a significant phenomenon for dementia care. While over a third of dementia caregivers do not work, among those who do nearly two out of three are working at least 35 hours per week. Among primary dementia caregivers, more are operating without help from friends or family (37.7 percent) than are (20.5 percent); this indicates that studies excluding secondary caregivers may leave out two out of every five informal roles in dementia care. Dementia caregivers report that one in five of their loved ones requires constant supervision.

*Hypothesis 1*

The first hypothesis from Chapter 2 states:

*H<sub>1</sub>: The age of dementia onset among care recipients varies by race.*

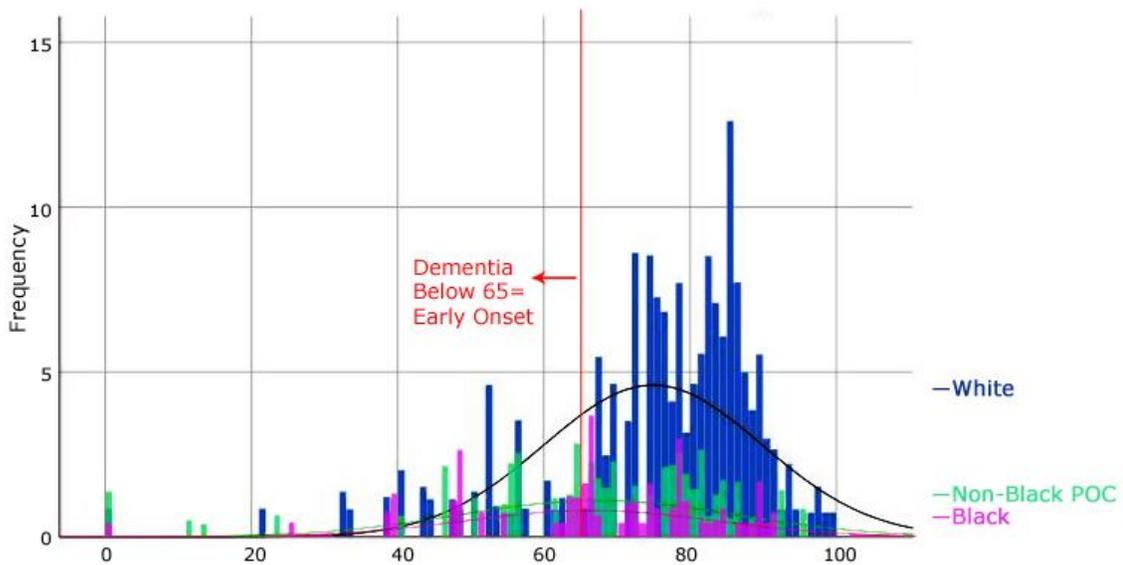
Recall that early onset dementia has a distinct pathological trajectory from those dementias that are recognized mostly beyond age 65. Table 3 shows the challenges discussed above with simplistic pathological determinants that ignore social phenomena, where age of onset appears to vary across race. *H<sub>1</sub>* can be explored (if not fully confirmed) using descriptive statistics. By comparing means across three categories of race (White, Non-Black Person of Color, and Black), age of care recipient and, by extrapolation, age of onset, reveal themselves to be much lower for people of color than for whites. The average white dementia care recipient is over seven years older (79.2) than the average person of color (about 71.5), and this disparity grows by another year when comparing age of onset (means: 75.1 for White and 67.0 for Persons of Color). Even though each of these race categories demonstrates about the same proportion in the dementia subpopulation as they do in the U.S. population, the dementia populations for people of color are far younger.

**Table 3.** Medians for Age of Onset, Controlled for Race, 2015 (NAC/AARP)

Variable ( <i>N</i> )	White (172)		Non-Black POC (52)		Black (35)	
	mean	Std. Dev.	mean	Std. Dev.	mean	Std. Dev.
Age of Care Recipient	79.2	13.43800	71.6	16.05000	71.5	14.55700
Age at Onset (est.)	75.1	14.95530	67.1	19.37383	67.0	16.96655
Early Onset	16.1%	.36855	36.5%	.48605	34.5%	.47908

When these figures are graphed, both the starkness of the distribution and its methodological limitations are apparent. Figure 1 shows the distribution of dementia

cases by calculated age of onset, controlling for race. The distribution curve for whites is the most robust, as it has the most cases, but it also distinctly crests far to the right of (higher than) Age 65, the benchmark for early onset dementia. The distribution curves for Black and non-Black people of color, on the other hand, crest very close to Age 65. These curves are rather flat due to their smaller number of cases. The significance of these findings must be tested via bivariate correlation.



**Figure 1.** Age of Onset, Dementia/Memory Problems (NAC/AARP 2015)

#### BIVARIATE CORRELATIONS

Measuring the significance of a relationship between categorical variables and linear variables calls for cross-tabulations; cross-tabulation measures the significance of relationships by measuring correlation between all categories of variables analyzed. Age of onset has too few cases spread across too many categories to compare as an interval-ratio variable, but its reduction to the early onset dichotomous variable can be utilized instead.

Table 4 reports the results of this comparison, confirming a significant, weak relationship ( $\chi^2$

= 12.302,  $\Phi = -0.218$  and Cramer's  $V = 0.218$ ).  $H_1$  is confirmed through controlled descriptive statistics. The age of dementia onset among care recipients is higher among people of color than among whites. Since nearly half of all cases of dementia for people of color are diagnosed before age 65, the early onset benchmark seems to conflate experiences that are not, in fact, the same.

**Table 4.** Cross-Tabulation of Age of Onset (Dementia/Memory Problems) by Race, 2015 (NAC/AARP)

Variable	All Dyads	White	Persons of Color
Early Onset			
No	77.4%	83.7	64.4%
Yes	22.6%	16.3	35.6%
Total	100%	100%	100%
N	259	172	87

$\chi^2=12.302, df=1, p\leq 0.001$   
 $\Phi=-0.218$  and Cramer's  $V=0.218, p\leq 0.001$

Before proceeding to regressions, the strength of other relationships related to this study's remaining hypotheses can be tested. Many have not demonstrated a significant relationship with the outcome variables, but those that do are reported in Table 5. Some moderate linear relationships are evident, notably the negative relationships employment status demonstrates with outcomes when stratified by a demographic; that is, non-Black persons of color who are employed tend to report significant lower levels of physical stress; also, an observed reduction in self-reported emotional stress for caregivers who are employed appears to be concentrated in women.

Controls reveal concentrations of relationship within specific categories. A negative relationship between employed caregivers and physical strain, for example, appears to be concentrated in caregivers who are neither white nor Black. As discussed in the literature review, research on non-Black people of color (recorded as Black, Hispanic, Asian, or Other)

is limited but has repeatedly suggested that communities of color have a strong sense of family duty that may mitigate stressors noted in general care populations. This assertion is especially common for Black caregivers, and yet they lack a significant relationship (even a negative one) here. Similarly, a negative relationship between employment and emotional stress appears to be concentrated in women. In both cases, the correlation coefficient may reflect social role fulfillment (communities of color fulfilling cultural expectations of family care, women who are relieved to have responsibilities outside the home) or it may reflect a low requirement of care: a caregiver who is able to work may not be overwhelmed by responsibilities at home, or they may have plenty of unpaid support to share the burden.

**Table 5.** Correlation Matrix of Select Caregiver Demographics and Outcomes, 2015 (NAC/AARP)

		Self-Reported Physical Strain (5-Level)	Self-Reported Emotional Stress (5-Level)	ADL Count (0-7)
	Std. Dev.	1.26160	1.17694	2.13535
<b>Demographics</b>				
Woman	.49480	-.099		
+Employed			-.225**	
White	.47325	.055		-.133*
+Recipient Under 65				-.174*
Non-Black Person of Color				
+Employed		-.329*		
<b>Care Traits</b>				
Recipient Under 65	.38124			-.180**
Parent-Child	.49997	.052	.181**	
Sandwich	.44051			
Employed	.48584		-.154*	

\* Correlation is significant at the .05 level (2-tailed).

\*\* Correlation is significant at the .01 level (2-tailed).

Note that these findings do not rule out a relationship between variables, only confirm the strength and direction of straightforward linear relationships. Table 5 shows only significant relationships that are unstratified or controlled for a single intervening

variable. Exploring more than two variables at a time (or three variables, if one is a control) requires a multivariate methodology, such as regression.

## MULTIVARIATE LINEAR REGRESSIONS

Multivariate linear regression measures the strength and direction of relationships between interval-ratio variables, dichotomous variables, or some combination thereof, using ordinary least squares to approximate a normal distribution and predict variance for a dependent variable. The remaining two hypotheses will be tested for significance through three models each of regression; if multiple models are found to be significant, the most elegant model (highest variance predicted with fewest variables) will be the most effective.

### *Hypothesis 2*

The second hypothesis from Chapter 2 states:

*H<sub>2</sub>: Dementia caregivers with normative characteristics will demonstrate less physical strain than non-normative caregivers.*

For dementia care dyads, the following traits are so common that their overlap may constitute a normative niche within dementia care: white, woman, over 50, higher income, not employed, caring for a parent. If the niche is significant, it could skew results for all non-normative caregivers. This hypothesis will be confirmed if some combination of the variables listed demonstrates a negative relationship with physical strain, but the higher the R<sup>2</sup> score, the more impactful the niche.

Results from three models are reported in Table 6. Model 2a is the simplest: what is the strength of the relationship between white woman and physical strain in dementia care? Model 2b includes all six of the variables listed to determine whether the niche gains significant accuracy with all factors included. Tweaking from among these six variables did

not improve significance much, so three further dichotomous variables are added for Model 2c: less education (high school diploma or less), normal onset (i.e., dementia care begins at or after age 65), and unpaid support. These three variables showed some significance when added to Model 2b individually, but their cumulative impact was strongest.

**Table 6.** Regression Models Predicting Normative Respondents' Self-Reported Physical Strain, NAC/AARP 2015

	Model 2a		Model 2b		Model 2c	
	<i>b</i>	$\beta$	<i>b</i>	$\beta$	<i>b</i>	$\beta$
Constant (Standard Error)	2.010 (.163)		2.025 (.236)		2.117 (.291)	
White	-.264 (.165)	-.099	-.308 (.168)	-.116	-.262 (.172)	-.098
Woman	-.168 (.158)	-.066	-.176 (.158)	-.069	-.172 (.158)	-.068
Over 50			-.193 (.173)	-.073	-.206 (.173)	-.078
HS or Less					-.124 (.169)	-.049
Higher Income			-.203 (.161)	-.080	-.253 (.177)	-.099
Not Employed			.280 (.166)	.108	.310 (.168)	.119
Caring for a Parent			.182 (.160)	.072	.191 (.165)	.076
Normal Onset					-.209 (.200)	-.069
Unpaid Support					.189 (.166)	.073
<i>R</i> <sup>2</sup>	.014		.044		.054	
<i>F</i>	1.852		1.920		1.573	
<i>N</i>	259		259		259	

*No result met the (1-tailed test) significance threshold of  $p \leq 0.05$ .*

This demonstrates that complex social factors (including, intersectionality would note, oppression) not only build upon one another in small, individual increments, they can also compound for an even greater effect than the sum of their parts. By adding more normative variables, we may get closer to demonstrating the hypothesis. Unfortunately, this sort of nickel-and-dime approach is discouraged in statistics — as the degrees of freedom increase,

the broad applicability of findings diminishes — and for this reason none of the models met the significance threshold.

Having failed to reject the null hypothesis, no normative niche is confirmed for this population of dementia caregivers. No significant relationship between normative caregivers and physical strain was observed. It appears that an analysis centered on normative social forces is not effective for demonstrating intersectional and othering dynamics among dementia caregivers.

### *Hypothesis 3*

The third hypothesis from Chapter 2 states:

*H<sub>3</sub>: Dementia caregivers with higher social marginalization will demonstrate a higher ADL index than other caregivers.*

To demonstrate that social forces from outside caregiving can still affect caregivers, some of the starkest social factors need to be discussed in their caregiving context. No studies have explored racism, sexism, or income inequality in the context of care dyads (although some reviews discuss homophobia in the context of LGBTQ caregivers, and as discussed above health research in general is embracing complex social and life course considerations), but these forces are inescapable because caregiving does not happen in a vacuum. Forms of discrimination and systemic oppression interact with one another, and intersectional analysis allows us to explore how. This test looks at ADL index, one of the most quantitative measures available for caregiver burden. To test whether the measure of multiple oppressions can be significantly predictive in the context of dementia care, disadvantaged demographic categories are tested: person of color, woman, lower income, less education,

employed, and sandwich generation. This hypothesis must demonstrate statistical significance before its measure of strength becomes relevant.

Table 7 reports the results of the three models tested for  $H_3$ .

**Table 7.** Regression Models Predicting Marginalized Respondents' Index of Activities of Daily Living Supported, NAC/AARP 2015

	Model 3a		Model 3b		Model 3c	
	<i>b</i>	$\beta$	<i>B</i>	$\beta$	<i>b</i>	$\beta$
Constant	2.010		2.025		2.117	
(Standard Error)	(.163)		(.236)		(.291)	
Person of Color	.601	.133	.631	.139	.599	.132
	(.279)		(.284)		(.283)	
Woman	-.183	-.042	-.206	-.048	-.219	-.051
	(-.267)		(.270)		(.269)	
Below 50K			.441	.102	.334	.077
			(.293)		(.282)	
HS or Less			.040	.009		
			(.289)			
No HS Diploma					.874	.102
					(.552)	
Employed			-.277	-.063	-.271	-.061
			(.279)		(.276)	
Sandwich			-.356	-.073	-.357	-.073
			(.308)		(.307)	
$R^2$	.020		.042		.051*	
$F$	2.557		1.811		2.244	
$N$	259		256		256	

\* $p \leq 0.05$  (1-tailed test)

Model 3a tests the significance of women of color's relationship with ADL index. Model 3b tests all seven variables listed at once. Neither demonstrates a significant relationship, yet Model 3b is close (its significance measured just outside the standard  $p$ -value for regressions,  $p \leq 0.05$ ). In this model, education was a surprisingly weak variable (far lower than in Model 2C); as stated above, the dichotomous split around high school diploma is very close to fifty-fifty, potentially offering too little variance to be significant. A new variable was recoded from the original dataset: a dichotomous measure for caregivers who had the least education (no high school diploma). Model 3c replaced the lower education variable for least education

and identified a significant relationship. In Model 3c, education becomes the most impactful predictor, alone accounting for variance of nearly one (0.874) ADL point — not a small difference for a variable with only a range of 6 and a mean of 2.1. This indicates that, among the most marginalized dementia caregivers (women of color with lower income who are employed and part of a sandwich generation), not having a high school diploma raises by almost one the number of ADLs performed daily.

It is important to clarify what the finding implies. It does not necessarily follow that the conjunction of some-but-not-all caregivers with marginalized predictors will experience the same impact or even the same kind of impact — intersectional interactions are contextual. A person without a high school diploma is more likely than a person with a diploma to come from a family facing tremendous disadvantage, socially and health-wise, so their loved ones tend to need much more from them on average. There is not likely to be any direct or indirect relationship between a caregiver's high school diploma and a present care recipient's care needs, but it might offer insight into how caregivers are selected.

It does not appear children from smaller families (therefore fewer available caregivers) attain less education than those with many siblings (in fact, the opposite seems more likely; Falbo & Polit 1986); more likely, a family who is choosing the caregiver for an elder with dementia may favor, among those available, persons with if not the least education, then the meagerest income or job prospects or the fewest meaningful accomplishments in the eyes of their family. Whatever an individual's personal reason for not finishing high school (“deliberately, accidentally, or even of necessity,” to quote Halberstam), by not pursuing the national baseline for education, the person may signal that

making more money is not a priority; such a person may live “outside the logics of capital accumulation” and thus be regarded by their family as one of Halberstam’s queer subjects (2005:10). In terms of economic contribution, a person who has very little education may be regarded non-normative, increasing the likelihood their family would thrust into another queer (subjectivity) role: that of caregiver.

Other disadvantages compound for even stronger effects, indicating that caregiving is susceptible to social and systemic marginalization. The possibilities warrant further consideration.

## CHAPTER V

### CONCLUSION

#### SUMMARY

This quantitative study presents a path forward for informal dementia care research in the United States. As demonstrated in the literature review, caregiving and dementia care have seen social inquiry languish while diffuse studies revisit pathology, demographics, and micro-interactions without coordination or innovation; this study makes a case for stronger centralization and utilization of theory and disciplinary frameworks in general and sociological and critical approaches specifically.

To demonstrate some of the practices here endorsed, this study performed an exploratory, quantitative analysis of social marginalization within a secondary dataset. Out of three hypotheses, two were confirmed: that age of dementia onset among care recipients varies by race ( $H_1$ ) and that dementia caregivers who are highly marginalized socially report performing more ADLs for their care recipients ( $H_3$ ). The other hypothesis, that a normative caregiver will report lower levels of physical strain, failed to attain significance. These hypotheses were informed by Halberstam's queer subjectivity, which asks if anyone who is not actively procreating and building capital can be othered in society, even if they are for reasons of family. These hypotheses were further developed through an intersectional lens to show that dementia caregivers do not exist outside the world of the social (and particularly of discrimination and systemic disparity), but instead have their care experiences affected by social factors outside the care dyad. These findings should inform future research and policy

priorities as the U.S. and other post-industrial economies approach a surge in elder populations and face new healthcare challenges in the decades ahead.

## DISCUSSION

Western philosophy can be historically located as a discourse that accompanies capitalism, and works to justify and rationalize a patently brutal and unjust system as inevitably scientific and organic. So seamlessly has capitalism been rationalized over the last two hundred years, in fact, that we no longer see the fault lines that divide black from white, work from play, subject from object.

*Judith (Jack) Halberstam*  
(summarizing *Lindon Barrett's* Blackness and Value: Seeing Double)  
In a Queer Time & Place, 2005, 8-9

One does not have to subscribe to the post-positivistic critical theories of Halberstam or Barrett or Foucault to perceive that the caregiver is both everywhere and nowhere in society. As thousands of generations have done before, families are stepping up every day to tend to loved ones who can no longer care for themselves, and yet society does not normalize caregiving or caregivers. Perhaps worse is dementia care; caring for someone who cannot recover and may one day forget you does not build families or make the family any money. Caregiving is an action outside of normative time and space — what is a bedtime when your loved one is sundowning? where is home when someone who once comforted you gets lost in their own body? are we allowed to care about things and people and relationships that society does not make an explicit time and space for, and if so how? This study does not ask those questions overtly, but they are present. If caregiving is going to meet the needs of elders in the coming decades, some of these tensions between the seen and the unseen, the valued and the unvalued, will require reconciliation.

Discrimination can include erasure as well as violence, but unlike homophobia, racism, and sexism, there is no term for the exclusion of people who prioritize care over

capital. Like many systemic otherings, it does not depend on the violent acts of individuals who wish harm, only broad inaction or negligence, facilitated by a general lack of inclusion, no normative time and space where one may be a caregiver and still be regarded as normative in society. This is especially true for dementia caregivers, whose support happens on a scale of years, not weeks, and who spend at least some portion of their time accommodating a fluid, subjective reality that may exist for no one else. Through the lens of Halberstam, caregiving emerges as queer subject, a (paradoxically social, in that it is the act of supporting another person) social deviant.

Informal care exists outside of the economy because there is no place for it within the economy, and yet that economy depends on free care labor. Its place is unwelcome, othered, queer, deviant. Caregiving is not inherently anti-capitalist, and yet the evidence presented here requires we ask whether capitalism might be anti-caregiving. If this is the case, caregivers would find themselves in good company; at the heart of capitalism as we know it is a hegemony that systemically (and sometimes overtly) disfavors women, people of color, workers, LGBTQ folks, asexuals, non-monogamists, couples who are childless by choice, and anyone who does not measure quality of life in dollars, years, or number of lives given, taken, or saved. At the heart of these others is a sense of mutualism, either because that is what capitalism rejects about them or in defense against the rejection. Is the caregiver — isolated, choiceless, sacrificing, yet steadfast — all that different?

The critical literature review presented supports developing standards and collaboration in care research and demonstrates the practice through a quantitative inquiry. Scholarship up to this point has been so diffuse one could call it anti-disciplinary, but by a

lack of intention rather than a deliberate deconstruction. Because this study has also acknowledged the relevance of post-positivistic approaches, it raises epistemological and ontological questions about creating new academic structures while accommodating post-structuralist knowledge and even priorities. In approaching this study with critical theories, my intention was to not overlook the process of othering in our social worlds; too many fields of research were built first and made accessible much later, but caregiving could be different. Caregiving, as much as sociology itself, is about people and for people, but can a foundation be built that leaves room for future discoveries and corrections?

Queer subjectivity empowers us to consider the possibility that caregiving is a transgression, and intersectionality tells us that transgressions face social punishment with material consequences. The theories employed in this study were selected because any mistakes of their application will be more informative than the correct application of uncritical social science. If it is found that the author has misappropriated queer subjectivity or Black feminism, then let the corrections be fluent and accessible and waste no time in creating space for caregivers, who may not even see themselves well enough to know they are no longer normative.

The quantitative analysis presented here is only a step in the direction of uncovering the full, non-normative mechanics of informal care. Many dementia caregivers face a powerful separation between their inner and outer inner worlds, but understanding of their lived experience can be improved if we expand the scope of inquiry to include the networks of support, the selection of individual caregivers by families, and the dense interdependence of the act of care itself. Demonstrating the commonalities within and between types of

caregivers (not only by condition, but also by social and cultural contexts) can reinvigorate scholarship but also deepen the connectivity of caregivers between themselves, giving them voice and their experiences validity.

$H_1$  confirms that caregiving, pathology, and social factors affect one another and warrant consideration together. The mean disparity in ages of onset between whites and people of color is severe enough, we are left to ask whether 65 is all that early for people of color; since early onset dementia has its own pathological trajectory, how can we know whether people of color are receiving the most appropriate medical response? The determination of early onset dementia may constitute a mechanism of systemic racism affecting healthcare and caregiving and warrants further examination. Critical theories beg us to go one step further and ask how the universal demarcation of age 65 contributes to the othering of people of color with dementia and therefore how it serves white supremacy.

The rejection of  $H_2$  discounts the notion of a normative dementia caregiver based on the most common caregiver demographics. This finding remains instructive about non-intersectional layering of identities: it is not enough to be most common; identity layering in research must be linked to specific (usually oppressive) social forces.

The findings for  $H_3$  return this inquiry to its intersectional perspective and confirm that, though small in this model, dementia caregivers can show marginalization in their work and/or selection.  $H_3$  expands evidence from  $H_1$  that social disparities interact with care circumstances. Unlike the pathological lens for  $H_1$  (i.e., the age that determines whether dementia is early onset or not), Model 3c presents only social relationships as predictors:

how is the person racialized and genderized, what is their economic and educational access, what responsibilities do they hold besides care.

This study confirms two hypotheses and fails to confirm one.  $H_1$  confirms that the pathology of dementia is affected in some way by racialization.  $H_3$  confirms that social determinants can directly correlate to care needs on the ground. The social lives of caregivers are significant to the course and outcomes of dementia care.

The prominence of caregivers seems poised to rise further as elder and disabled populations come to represent a more significant segment of society; however, such an emergence challenges normative family and economic priorities. Scholars cannot deny that care dynamics demonstrate social influence, nor that quantitative research benefits from consideration of intersectional compounding of normative/non-normative othering. Nor can dementia caregivers see their circumstances only through the lens of one sick relative: the circumstances of dementia care are just as systemic as they are personal.

## LIMITATIONS

By emphasizing that new truths available in a secondary source, this study forgoes the opportunity to ask further questions from participants or researchers involved. Its emphasis on dementia care will also limit the reliability of results for other types of caregivers. Findings will only be directly applicable to experiences within the United States and may not accurately reflect trends in other countries.

The design of this study is nascent and requires further development. That said, these choices have been made deliberately to specifically highlight gaps in existing literature,

outline opportunities for methodological innovation, and more effectively elucidate the social lives of informal dementia caregivers.

## RECOMMENDATIONS

Developing a stronger sociological base for care research will require the development of both knowledge and design; before caregiving can begin to consider standardization under sociology or some other field, some cohort of investigators will have to agree that this is worthwhile and commit to building bridges between the research niches that currently exist. These bridges will require social scientists to become more familiar with biomedical scholarship (and vice versa) and to improve social inquiry of the middle ground between the four farthest corners of care scholarship: hyperlocal qualitative, logistical biomedical practice, aloof quantitative demography, and abstract theory. Researchers may also develop interdisciplinary or trans-disciplinary research that links caregiving trends with links to relevant inquiries in other fields, such as generosity (anthropology), non-romantic interdependence (psychology), and mutual aid (political science). These approaches all have something to show one another, but without networking across all levels care research will remain anti-structural and anti-disciplinary.

While building a framework for care research that crosses levels and disciplines could help to fill research gaps, some of the limitations could be improved by implementing more theoretical approaches that contextualize individual care dynamics in greater economic and power trends. By exploring the concept of normativity, I attempted to place the positivistic in conversation with the post-positivistic, but such an undertaking will require a larger dataset or tighter construct of normativity to gain significance. Researchers would do well in

such an undertaking to make it clear that defining normativities creates others out of the non-normative; though the outcomes are vastly different, there is a fine line between detailing existing disparities and reinforcing them.

The health of greater families and support systems cannot be discerned from any available caregiver dataset, but the present findings bolster the case for more comprehensive inquiry of whole networks and systems around dementia care, not only the primary dyad. Understanding the dyad requires a more systemic reflection on the dyad's familial support and circumstances. However, even in available datasets, these findings can be expanded by controlling for family versus non-family care dyads (particularly  $H_3$ ).

Both theoretical frameworks employed here have stronger origins in interpretation than in quantitative analysis. This confluence of methods may be off-putting to readers who prefer one ontology or another — positivism, or post-positivism — but it should nonetheless inform future endeavors in social theory, quantitative intersectionality, and mixed methodologies.

The techniques utilized here found weak significant results; future studies may consider linking intersectional approaches with other multivariate techniques, such as factor analysis, cluster analysis, and try to improve upon these findings. Although the NAC/AARP dataset was selected for its breadth of both demographic and subjective variables, this study warrants repeating with a larger (probably federal) dataset, such as the *National Survey of Caregivers*. Politicization affects what research is performed and shared from the federal level; non-federal secondary datasets can aid in filling potential gaps, but would be bolstered if

they were more normalized in academic literature and their range and complexity taught, assessed, and evaluated as part of graduate level social science education.

Research into how dementia is framed in popular culture may help to alleviate the disconnect and elevate the agency of people in early stages of dementia and the humanity of those in late stages. For all the reminders in dementia care scholarship that dementia is not a mental illness, it is still socialized like one. Such research may want to invoke the literature of disability studies, particularly calls to amplify the voices of disabled people in defining their own experiences.

Finally, and perhaps most importantly, researchers need to incorporate a stronger sense of stakeholder in studies of caregiving. The researcher and the medical practitioner offer important insights but can still overlook elements of care that may be more apparent to caregivers, their extended support system, and even persons with dementia themselves. Only by including multiple (and, ideally all) of these perspectives will care research advance beyond its heretofore reactive stance.

## CONCLUSION

As this study was being completed, the world took on great, collective, health-anxious gasp as a new and highly contagious virus transversed every populated continent. While epidemiologists go to work to inform the public and mitigate the impact, topics of mutual care and social isolation are suddenly prominent and urgent. Where those conversations lead remains to be seen, but somewhere between the panic and the boredom there have also been indications that not everyone who beats COVID-19 is able to fully recover. It is too early to tell what the impact will be upon the elder population — a high

enough death rate for people over 65 could completely upend predictions of a “care gap” — but two other populations are changing in demographically significant ways. Firstly, in the United States, elders of color (especially Black men) have been the most likely to die in the first wave of COVID-19, as decades of continued health disparity and systemic disadvantage take their toll. Secondly, there is a growing likelihood that some portion of COVID-19 survivors will become permanently disabled in ways that have not yet been identified, creating a new care recipient population of unknown scope.

Caregiving has always been relevant, but never more urgent than right now. How we care for others and expect to be cared for may set the stage for the next century of social habits, expectations, and connections. From dementia caregivers, we can learn to accept a reality that is not entirely our own, to recognize and respect the agency of others, and to develop and sustain strong support systems — informal and formal — that serve all participants well.

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