Time and Again:

Old Women and Care Workers Navigating Time, Relationality, and Power in Dementia Units

By

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DISSERTATION

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This dissertation is dedicated:

To my dad, Edward Gibbons, my aunt, Mary Fulkert, and my grandmothers, Setsuko Gibbons and Annette Fisher.

To Euteva, the first old woman with dementia I befriended.

And to Sylvia, who sustained me throughout my fieldwork and with whom this project begins and ends.

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LIST OF ABBREVIATIONS

AAC	Augmentative and Alternative Communication
ADL	Activity of Daily Living
ASCU	Alzheimer's Special Care Unit
ASL	American Sign Language
CMS	Centers for Medicare & Medicaid Services
CNA	Certified Nursing Assistant
HCBS	Home and Community-Based Services
IADL	Instrumental Activity of Daily Living
LAR	Legally Authorized Representative
LTSS	Long-Term Services and Supports
PPE	Personal Protective Equipment

SUMMARY

In the United States, there are nearly one million old disabled women living in nursing homes, approximately seventy percent of whom are diagnosed with Alzheimer's disease and other forms of dementia. The vast majority of their direct care workers are also women, and many are further marginalized by race, class, and immigrant status. Despite this, little is known about the lived experiences of old women with dementia and care workers in nursing homes. This project centers the care relationships between institutionalized old women with dementia and the immigrant women of color employed to care for them. Drawing on nine months of ethnographic research in the dementia unit of a nursing home, I focus on temporality as a framework to understand the complex ways care is conceptualized, structured, and enacted within the confines of the unit. I argue that while bureaucratic and institutional time serve as a nexus of power and a pervasive organizing principle of care structures and relations within nursing homes, old women with dementia and their caregivers disrupt these normative, dominant, and linear approaches to temporality. They do this by slowing institutional time to "make time" for connectivity, engaging in circular and repetitive forms of relationship building, and existing together in what I term "dementia time," which is a temporal dis/orientation that explores alternate spacetimes and realities and finds meaning and value in self-contained, nonlinear, intermittent, irrational, and idiosyncratic moments. This research has theoretical and applied implications regarding how disability, aging, and feminist studies understand temporal constructions of care and how a more just system of care might be enacted for multiply marginalized women giving and receiving care in dementia units.

I. INTRODUCTION: "IN THE TIME OF DEMENTIA"

"We are living in the time of dementia. As we live longer than ever before, dementia touches the lives of more of us than ever before." – Anne Basting

Dementia[1] is one of the most feared conditions in modern American society, largely due to its defining characteristics of memory loss, disorientation, confusion of time and place, and increasing dependency (Yoshizaki-Gibbons, 2017). This fear is not without consequences for the nearly six million people in the United States living with dementia—a number that is expected to increase as medical and public health advances foster greater longevity. The individual, cultural, and societal anxiety around the presumed loss of self that accompanies memory loss supports narratives of control and discipline that materialize in the forms of isolation, erasure, and dehumanization. Biomedical understandings of dementia, which largely dominate American society, simultaneously cast dementia as a tragic individual medical condition and a looming epidemic that burdens families, communities, and society at large (Innes, 2009; Peel, 2014).

Presently, the majority of people with dementia receive care in home and community-based settings. However, dementia places many old people at risk for institutionalization, as family caregivers struggle to care for people with dementia without adequate physical, financial, emotional, and social supports. The Alzheimer's Association (2020a) reported that "an estimated 70% of older adults with Alzheimer's or other dementias live in the community, compared with 98% of older adults without Alzheimer's or other dementias" (p. 52). Consequently, many elders in nursing homes have a diagnosis of Alzheimer's or another form of dementia (Centers for Disease Control and Prevention,

[1] Dementia refers to a range of neurocognitive conditions, and although Alzheimer's disease is the most common, there are many forms. To account for this variation, the Alzheimer's Association (2020a) defined dementia broadly as "a general term for loss of memory and other mental disabilities severe enough to interfere with daily life" (para 1).

2014a). The Alzheimer's Association (2020a) further specified that by age 80, admission into a nursing home is "expected for 75% of people diagnosed with Alzheimer's dementia, compared with only 4% of the general population" (p. 426). Given that women have a longer life expectancy than men and are more likely to be diagnosed with dementia, a significant proportion of the 1.3 million old disabled people confined in nursing homes are old women with dementia (Harris-Kojeti et al., 2019).

Additionally, the vast majority of their direct care workers are also women, and many are further marginalized by race, class, and immigrant status. There are currently more than 1.6 million people working in nursing homes caring for old disabled people, most of whom are direct care workers such as Certified Nursing Assistants (CNAs).[2] According to the Paraprofessional Health Institute (2019), approximately 90% of CNAs in nursing homes are women. The majority are also people of color: 37% of CNAs are Black, 12% are Latinx, 4% are Asian or Pacific Islanders, and 4% are indigenous, multiracial, or identify as other races and ethnicities. Furthermore, 21% of CNAs in nursing homes are immigrants (Paraprofessional Health Institute, 2019). These marginalized care workers engage in important, difficult labor, often for low wages, inadequate benefits, and limited supports. The relationships between old people with dementia and care workers reflect what Elana Buch (2018) referred to as "inequalities of aging"—or the ways in which caring for an aging population intersects with intensifying social injustice. Thus, more than an individual diagnosis, dementia is a cultural phenomenon (as noted above by Anne Basting), with impacts on families, the labor force, the long-term care industry, and consequently, society at large.

[2] CNAs are the frontline direct care workers who assist old and disabled people with dressing, bathing, eating, and other daily tasks.

In this project, I center the care relationships between institutionalized old women with dementia and the immigrant women of color employed to care for them in the dementia unit of a nursing home. As institutions, nursing homes are complex places. Old people with dementia in nursing homes are ideally able to receive round-the-clock care, participate in programs and activities tailored to their capacities and interests, develop relationships with care workers, and be in community with others with dementia. Care workers are ideally able to meet the physical, social, and emotional needs of residents, engage in meaningful relationships with residents, and earn a living. However, nursing homes are often sites of isolation, monotony, debilitation, exploitation, neglect, abuse, and other forms of violence for the care dyad. Special care units for those with dementia add an additional layer of complexity as these units are designated specifically for residents with dementia and are often secured (i.e., locked). Unfortunately, little is known about the lived experiences of old women with dementia and care workers in nursing homes or how they develop and enact care relationships in the context of a dementia unit of a nursing home.

I engaged in this research with the intent of gaining a deeper understanding of how institutional, cultural, social, political, and structural factors influenced the care relationships between old women with dementia and care workers. I wanted to explore how their social identities—disability, age, gender, race, class, and immigrant status—intersected with structures of care to mediate their lived experiences and relationships within the context of the dementia unit. As I conducted my research, I began to uncover how time operated in complex ways in the unit, as it was a pervasive form of power that the old women with dementia and the care workers had to navigate.

Consequently, I focus specifically on temporality as a framework to understand the diverse ways old women with dementia and their caregivers are gendered, racialized, classed, aged, and disabled within the context of the dementia unit, and the ways this

subjugation often occurs relationally as well as culturally and structurally. Drawing on nine months of ethnographic research in the Alzheimer's Special Care Unit (ASCU)[3] at Cedarwood Care Center,[4] a highly rated non-profit Jewish nursing home in the Chicagoland area, I analyze how time simultaneously operates to reproduce gendered, racialized, classed, aged, and disability oppressions and serves as a site of solidarity, community-building, and resistance among old women with dementia and their caregivers.

A. **Time in Dementia Units of American Nursing Homes**

During lunch one day, Sylvia,[5] a resident in the ASCU of Cedarwood Care Center, spilled orange juice all over her shirt and pants. When lunch ended at 12:30 p.m., Stella, a middle-aged Black American CNA, noted she needed to change Sylvia, but she also needed to take care of a few other residents first. Stella was one of four CNAs that day for 48 residents—meaning that Stella was responsible for meeting the needs of 12 old people with dementia during her shift. Some of Stella's assigned residents needed to use the bathroom or be transferred in and out of bed, so Sylvia's need was considered a lower priority. Stella felt bad she could not assist Sylvia right away, but a CNA's job is often one of triage, and care workers must rank the needs of residents and attend to them according to urgency. Sylvia keeps pulling at her wet sweatpants. "This is terrible," she announces. "She kept wept coming back wet. I can eat five, but I can't remember they were five."

Sylvia, a former schoolteacher, is an 88-year-old white Jewish woman with dementia. She has lived in Cedarwood Care Center for many years. All the care workers absolutely adore Sylvia. A widow of nearly 20 years, Sylvia is the mother of three children –

[3] ASCUs are also referred to as dementia units or memory care.

[4] Cedarwood Care Center is a pseudonym.

[5] All names of the old women with dementia and care workers are pseudonyms.

none of whom come to visit her. When Sylvia was younger, she was diagnosed with "severe and persistent mental illness" and the staff wonder if this is the reason her children do not visit. Even so, the care workers do not hold this possibility against Sylvia. As Karina, a middle aged white Eastern European immigrant CNA observed, "Maybe [the children] have trauma and seeing her is too hard but it still makes me sad because that's not who she is now."

At 2:15 p.m., Stella finally makes her way back to Sylvia, and brings a fresh pair of clothes from Sylvia's apartment.[6] Stella places the clothes next to Sylvia as she unlocks her wheelchair. Sylvia is known for her beauty and fashion in the dementia unit, and she picks up the outfit Stella has brought and throws it on the floor, declaring, "These are awful!" Stella asks, "You don't want to wear them, Sylvia?" "No." Unfortunately, Stella does not have time to return to Sylvia's room and fetch a new outfit or take Sylvia to her room to see what she would like to wear—some of her other 11 residents are still waiting on her. Stella takes Sylvia into a nearby empty room and helps her use the bathroom and then changes her clothes. Stella talks with Sylvia the entire time, telling her what she is doing and affirming her. Stella brings Sylvia back. Sylvia is all smiles. She kisses Stella's arm. "You are wonderful!" she tells her. Stella smiles. "So are you!" She hands Sylvia a weighted baby doll[7] and rushes off to care for the next resident.

Sylvia turns to me. "They put me in here. Free me. Otter. Otter. Daughter. Please." "I wish I could Sylvia," I respond. "Oh, is this your baby?" "Yes," Sylvia tells me. "How cute!

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[6] The care workers often used the term "apartment" to refer to residents' rooms. The rooms were private, but they were single rooms.

[7] "Doll therapy" is a controversial therapeutic practice in dementia care that involves providing dolls to people with dementia with the goal of increasing quality of life and alleviating distress. It is considered a nonpharmacological treatment for "challenging behaviors" (for a disability studies critique of behaviorism, see Roscigno, 2019). Much of the support for doll therapy is anecdotal, but there is some empirical evidence it is beneficial (for an overview, see Mitchell & O'Donnell, 2013). Critics of the practice note that it is demeaning and infantilizing for adults with dementia.

What is your baby's name?" I ask. "Freedie Joy Fader. Until someone brings us. Come home. And they'll go away. She has to go until I go, go home. It was twenty. Twenty." I nod in agreement. Sylvia continues, "It's probably more morning. This is the thing that has to be earned. Can I do that without the trip? Is a seagull coming?" "I hope so," I tell Sylvia. "Yes," Sylvia agrees. She then begins counting. "One. Two. Three. Four. Five. Six." "Seven!" Another care worker, Ashanti, a middle-aged Black African immigrant CNA calls out. She is walking by and stops to squeeze Sylvia's hand. "Seven, my dear Sylvia!"

I share this story about Sylvia to illustrate the many ways Sylvia's life as an institutionalized old woman with dementia was defined by time:

- The amount of time she lived in the dementia unit, segregated from society;
- The time until her anticipated death, which dictated what services she did—or did not—receive;
- The strict and inflexible daily routine of the institution which dictated her daily schedule;
- The amount of time she had to wait for care;
- The time the care workers made for her;
- The time she gave to others, the care workers and the other old women with dementia; and
- The times and spaces she entered, which differed from the realities of those around her.

In this project, I explore the temporal dimensions of dementia care in an institution, centering on how time is structured and how it mediated the care relationships between old women with dementia, like Sylvia, and care workers, like Stella and Ashanti.

B. **The Temporal Constructions of Dementia and Care**

As an age-related cognitive impairment, dementia is highly associated with time, particularly in medical and cultural discourses. Physicians and medical researchers are concerned with time of dementia onset, slowing the progression of dementia, and time from diagnosis until death. Family members and friends lament the "lost time" that their loved ones with dementia experience due to memory loss, and struggle to “reorient” people with dementia to the "reality" of the present day and time (Beard, 2004). Caregiving for someone with dementia has been described as so difficult that it feels endless, resulting in a book about caregiving titled "The 36-Hour Day” (Mace, 2012). Policy makers and advocate groups warn of the inevitable "dementia time bomb," and caution that society is unprepared to deal with the rapidly growing number of people with dementia and the social, physical, and financial burdens they place on others (Spencer, 2016). Thus, interpersonally and societally, dementia is largely constructed in relation to timescapes, such as time frames, temporality, timing, tempo, and duration (Adam, 2008).

Dementia is not unique in this regard, as many forms of impairment and illness are framed within narratives of time. According to Kafer (2013), “Familiar categories of illness and disability--congenital and acquired, diagnosis and prognosis, remission and relapse, temporarily able-bodied and ‘illness, age, or accident’--are temporal; they are orientations in and to time” (p. 26). Kafer (2013) uses this temporality as a starting point to explore disability and its connection to time, querying how thinking about time may lead to new directions in disability studies scholarship and activism. In this project, I take up Kafer’s (2013) call for further exploration of the ways in which temporality and disability intersect.

I argue that while the dominant temporalities of clock time, bureaucratic time, and institutional time[8] serve as a nexus of power and a pervasive organizing principle of care structures and relations within nursing homes, old women with dementia and the care workers disrupt these normative, dominant, and linear approaches to temporality. They do this by "making time" for and "giving time" to one another, engaging in circular and repetitive forms of relationship building, and existing together in what I term "dementia time," which is a temporal dis/orientation that explores alternate spacetimes and realities and finds meaning and value in self-contained, nonlinear, intermittent, irrational, and idiosyncratic moments. Examining the diverse ways temporality pervades the culture and structure of the dementia unit and influences the care relationships between old women with dementia and their caregivers provides unique insights into the ways oppression and resistance operate at the intersections of race, gender, class, immigration status, age, and disability in the context of nursing homes.

Furthermore, this dissertation seeks to deepen our understanding of what Liat Ben-Moshe (2011) has termed "diverse sites of confinement" —an expansive category which recognizes that prisons are not the only form of confinement in the U.S., and includes nursing homes, psychiatric hospitals, and institutions for people with intellectual disabilities. The lack of attention to diverse sites of confinement results in researchers and activists (re)producing the unknowability and invisibility of institutionalized people who are marginalized by disability and age, as well as race, gender, and class. It also contributes to the unknowability and invisibility of the people who care for old and disabled individuals, many of whom are marginalized by race, gender, class, and immigration status.

[8] See Chapter IV: Dominant Temporalities in the Dementia Unit

Lastly, this project aims to bridge disability studies, critical gerontology, and feminist theory to better understand experiences of care and confinement. Within many theoretical considerations of care, dementia is rarely considered, particularly within disability studies and feminist theory. Disability studies has historically focused on young and middle-aged disabled people and has failed to understand the unique care experiences of disabled elders. Furthermore, feminist theory has highlighted that care is a gendered, racialized, and classed experience, but often focuses singularly on caregivers, and thus ignores the experiences and positionality of disabled and old people. Conversely, disability studies scholarship and activism sought to center the disabled person in theoretical considerations of care but has done so in a way that disregards the care provider and the material contexts in which people give and receive care in an era of neoliberal, transnational capitalism. Consequently, these bodies of knowledge on care are on parallel paths, and rarely interconnect. My dissertation aims to address this issue by centering the care relationship rather than either side of the care dyad, and in doing so bridge disability, aging, and feminist studies and place them in conversation with each other.

C. **Time and Place**

This project about time is also situated in a particular time and place. My fieldwork in the dementia unit of Cedarwood Care Center occurred over nine months in 2018-2019, prior to the global pandemic caused by the novel coronavirus COVID-19. The pandemic has changed American society in countless ways and brought into sharp relief inequalities of race, gender, class, age, and disability. Old disabled people and care workers living and working in nursing homes have long been invisible and disregarded in society, which was a key factor in my desire to do an ethnographic study of a nursing home. Yet the pandemic has revealed how many of the issues discussed in this study—such as understaffing, low

pay, overcrowding, a lack of resources, and privatization—in nursing homes have created significant vulnerabilities for old disabled people and care workers that have resulted in increased isolation, illness, debilitation, and death. In Illinois, more than 40% of COVID-19 related deaths have been associated with long-term care facilities (Bradley, 2020). Nationwide, approximately 33% of people who have died from COVID-19 were nursing home residents, but researchers are estimating that as the pandemic continues, nursing home residents will represent closer to 50% of all COVID-19 related deaths (Cunningham, 2020).

Under capitalism, the "value" of old disabled people and care workers is located in their bodies, which are used to generate profits for the nursing home industry and larger medical industrial complex[9] (Russell, 2019). Their bodies are debilitated over time and understood as replaceable and disposable (Livingston, 2005; Puar, 2017). The manufactured crisis of scarce medical resources under COVID-19 has created a context of fear and death, and consequently, the disposability of old disabled people and care workers has been heightened (Wong, 2020). Across the United States, nursing home residents and care workers are being denied access to COVID-19 testing, personal protective equipment (PPE), fair wages, and hazard pay (Gerety, 2020; Kelly, 2020). In discussions of medical rationing, or the practice of restricting some people's access to health care due to scarcity, old disabled nursing home residents are the among the first to be identified as low priority—the implication being that they have lived their lives and are now out of time (Keliddar et al., 2017; Kohn, 2020; Shurkin, 2020). This project has numerous policy implications for

[9] According to Mingus (2015), the medical industrial complex "is an enormous system with tentacles that reach beyond simply doctors, nurses, clinics, and hospitals. It is a system about profit, first and foremost, rather than "health," wellbeing and care. Its roots run deep and its history and present are connected to everything including eugenics, capitalism, colonization, slavery, immigration, war, prisons, and reproductive oppression. It is not just a major piece of the history of ableism, but all systems of oppression" (para 3).

dementia care, and these implications are particularly important in the midst of COVID-19. Given this, although fieldwork occurred more than a year prior to the pandemic, I return to COVID-19 in the conclusion to discuss how my research has implications for the present moment and the future.

D. **Overview of Chapters**

Prior to delineating the ways in which the old women with dementia and the care workers navigated temporality, relationality, and power in the dementia unit, I situate this project in several existing bodies of knowledge and detail my research methodology and methods. In Chapter II: Literature Review, I explore the theoretical, practical, political, economic, and social dimensions of dementia and dementia care. I examine how academic discourses such as mainstream gerontology, critical gerontology, humanistic gerontology, aging studies, and disability studies have approached and understood dementia in disparate ways, often with limited interdisciplinary collaboration. Furthermore, I highlight how old people with dementia have been ignored and excluded within disability studies despite disability studies' significant potential to transform how we view and treat old people with dementia. I then discuss scholarship on the lived experience of dementia, noting that historically the experience of dementia has been narrated by medical professionals and caregivers and when people with dementia are included, they are usually community-dwelling, privileged across axes of gender, race, and class, and experiencing fewer impairments than institutionalized old people with dementia.

Next, I examine theoretical approaches to care, including feminist ethics of care, disability studies' rejection of care and focus on independence and interdependence, and gerontological approaches to care, including person-centered care and care grounded in citizenship, human rights, and social justice frameworks. Then, I describe the ways in which

policy and funding have influenced the provision of dementia care in institutions such as nursing homes. Subsequently, I examine the culture of dementia units and long-term care and provide an overview of ethnographic explorations of nursing homes and dementia units—none of which have drawn explicitly from disability studies or feminist theory. Lastly, I consider how social identities such as age, disability, race, gender, class, and immigrant status influence dementia care. I reveal how much of the literature on dementia and institutional dementia care focuses on either old people with dementia or care workers, but rarely centers their care relationships and the social, cultural, political, economic, and structural factors that mediate these relationships.

In Chapter III: Methodology and Methods, I discuss the origins of this project, including the purpose, guiding research questions, and the theoretical approach in which my research is grounded. Next, I provide an overview of ethnographic methodology, elucidating the reasons feminist quasi-ethnography was an ideal methodology for research in a dementia unit. I also explore how my positionality influenced my research. Then, I describe the dementia unit and Cedarwood Care Center and detail my processes for recruitment, sampling, data collection, data analysis. Additionally, I consider how I maintained quality and rigor and the limitations of this study. I end this chapter my noting how the deep engagement permitted by ethnographic methodology allowed me to uncover the importance and complexities of time, relationality, and power in the dementia unit.

In Chapter IV: Dominant Temporalities in the Dementia Unit, I delineate three forms of dominant time—clock time, institutional time, and bureaucratic time—that created the structures of care in the dementia unit. I argue that these temporal constructions were a pervasive form of power in the dementia unit and regulated the care relationships between the old women with dementia and the care workers. Clock time, institutional time, and bureaucratic time intersect to establish an “economy of time.” Within this temporal economic

context, time is constructed as a scarce, valuable commodity that is highly controlled, regulated, and structured. Time was sought after, competed for, given, and denied in ways that influenced the care relationships between the old women with dementia and the care workers and their material lives. I highlight the ways the old women with dementia and the care workers perpetually struggled to have and give "enough time" to meet their bodily, emotional, mental, financial, and social needs.

In Chapter V: "Gifts of Time": Making and Giving Time in the Dementia Unit, I further uncover how the dominant temporalities of the dementia unit controlled how the old women with dementia and care workers "spent" their time within the economy of time. I detail how clock time, institutional time, and bureaucratic time warped their phenomenological experiences of time and limited how much self-determination they had over how to use and structure their time. I then draw on feminist disability studies theories and politics of temporality and relationality to consider what it meant to make time for and give time to each other in this context. I argue that by giving and making time in the dementia unit, the old women with dementia and the care workers disrupted and resisted the dominant temporalities and strengthened their interdependent care relationships.

In Chapter VI: (Re)building Relationships through Dementia Time, I continue to explore the temporal aspects of the care relationships between the old women with dementia and the care workers by forwarding the theory and practice of "dementia time." I situate dementia time as an expansion of crip time and queer time that challenges dominant and normative constructions of time. I assert that dementia time is a temporal dis/orientation that centers connection, solidarity, and relationship (re)building by focusing on a particular moment in time and place and remaining flexible as moments pass and needs change. In dementia time, these moments in time may be self-contained, nonlinear, intermittent, irrational, and idiosyncratic - yet they are no less meaningful or valuable. I propose four

overlapping tenets of dementia time: (a) focusing on the moment; (b) maintaining rhetoricity to practice inclusion and affirm personhood; (c) acknowledging and respecting situated realities; and (d) emphasizing a politics of collectivity and care. Lastly, I consider the challenges and complexities of dementia time as a potential site of liberation.

I conclude with Chapter VII: Time to Care. I initially reflect on how temporality, relationality, and power became the focal points of this project. I then highlight the major contributions of my research and advocate for old people with dementia and care workers to be centered in interdisciplinary theories of and approaches to care. Next, I discus the implications of this project and contend that it is “time to care” about old people with dementia and care workers in nursing homes, who deserve to be supported economically, socially, politically, and culturally—a need that became particularly clear in the midst of the COVID-19 pandemic. Lastly, I contemplate future directions for this work.

II. LITERATURE REVIEW

This project engages with several bodies of knowledge: (a) conceptualizations of dementia in academic discourse; (b) lived experience of dementia; (c) theoretical approaches to care for people with dementia; (d) dementia care in long-term care/institutional contexts; (e) the culture of dementia and institutional long-term care; and (f) dementia, care, and social location. I first define dementia, and then discuss the existing literature for each area. Lastly, I explore gaps in the literature.

A. Defining Dementia

Despite its common usage in everyday life, dementia is difficult to define. As Zeilig (2013) observed, “Even in medical and scientific texts, dementia is conceptually slippery; it retreats from and resists definition…[Dementia] cannot be easily defined because [it has] been subject to subtly changing psychiatric, biomedical, and social/cultural stories” (p. 260). In other words, although dementia typically has a medicalized definition, it is contingent on many social and cultural understandings. Broadly speaking, dementia is an umbrella term for a range of neurocognitive conditions. In terms of impairment, dementia is most frequently associated with memory loss, but also manifests in other ways, such as: experiencing confusion of time or place; struggling to complete familiar tasks at home or work; having difficulty planning or problem solving; having problems with speaking or writing; exhibiting poor judgment; withdrawing from social activities; and experiencing changes in mood or personality (Alzheimer’s Association, 2020a).

The most common cause of dementia is Alzheimer’s disease; other types of dementia include vascular dementia, dementia with Lewy bodies, and frontotemporal dementia. Additionally, people with Parkinson’s disease, Huntington’s disease, and Down syndrome and people who have had strokes or traumatic brain injuries are at a higher risk

of developing dementia (Alzheimer's Society, 2016). Age is considered a primary risk factor in the development of dementia, and the older a person is, the greater the likelihood they will have dementia. According to Chen, Lin, and Chen (2009), the prevalence of dementia in Western countries increases from 1-3% among people 60-64 years old to 35% among people over the age of 85. Currently, more than 5.8 million people in the United States have some form of dementia and the number of people with dementia in the U.S is expected to increase to 14 million in 2050 (Alzheimer's Association, 2020a). Consequently, dementia is one of the leading causes of impairment in adults aged 65 and older (Priestley, 2003).

B. Conceptualizations of Dementia within Academic Discourse

Since the 1900s, dementia has increasingly been included within the purview of academic discourse (Ballenger, 2006). Several key fields of study examine and explore dementia and related issues, including gerontology, critical gerontology, humanistic gerontology, aging studies, and disability studies. However, each field conceptualizes and approaches dementia in different ways. Furthermore, while some of these fields have centered dementia as a significant area of research and scholarship, dementia remains in the periphery of others. Given that one of the aims of this project is to integrate theories of aging and disability, it is essential to understand how each field approaches the study of aging and old age, and how that approach influences the way the field theorizes about dementia and, more broadly, disability.

1. Mainstream Gerontology

Generally speaking, gerontology is the study of the aging process and older adults. According to Bass (2009), "Gerontology sought to bridge the worlds of life sciences, medicine, and the social sciences in a comprehensive view of the aging individual within a larger societal context" (p. 349). Since the discipline's beginning in the 1940s, gerontology

has branched off into several sub-fields, including critical gerontology, humanistic gerontology, and aging studies. I use the term “mainstream gerontology” to refer to the dominant theories, models, and frameworks in the field, with a particular emphasis on scholarship that aligns itself with the medical and natural sciences and thus claims to produce objective knowledge.

Within mainstream gerontology, there is recognition that aging is a biopsychosocial process with three broad contributing factors: biological influences (disease and disability), individual influences (psychosocial and behavioral), and social structural influences (gender, socioeconomic status, race, age, and cultural context) (Bengston et al., 2009). As disability is classified as a biological factor, it is not understood as a social construction or social structural factor. Thus, mainstream gerontology primarily adopts medical and functional model approaches to disability. In doing so, mainstream gerontology has contributed to the medicalization of dementia and other disabilities. According to DasGupta (2015), medicalization of disability “refers to how individuals with disabilities have been categorized as ‘sick’ and placed under the jurisdiction of the medical establishment and medical professionals” (p. 120). Medicalization results in an effort to diagnose, prevent, and treat.

This medicalized approach to dementia and other disabilities is embedded in mainstream gerontology’s dominant theories and paradigms of aging. The gerontological persuasion, or the “biomedical and social scientists, policymakers, activists, and entrepreneurs interested in the ‘gray market’” (Ballenger, 2006, p. 56), has been effective in promoting ideas such as “normal aging,” “healthy aging,” and “successful aging” as ideals for which to strive. For instance, in regard to normal aging, Heller and van Heumen (2013) explained, “Normal aging has been described as encompassing those age-related changes that are expected and inevitable and in understanding that changes that cause diseases or inability to function are not part of aging” (p. 7). In other words, researchers intended to

prove that the experience of decline was age-related rather than age-caused, and thus, not an inevitable part of the aging process. Relatedly, healthy aging is defined as “the maximal delay of illness, disease, disability, and hence mortality” (Bengston et al., 2009, p. 8). To further the idea that disease and disability are not part of “normal aging” or “healthy aging,” older adults who did experience disease and disability had their aging processes classified in another category—“pathological aging” or “abnormal aging.” Dementia is considered a prime example of pathological and abnormal aging.

Successful aging is defined as: “avoidance of disease and disability, maintenance of cognitive and physical function, and sustained engagement with life” (Rowe & Kahn, 1998, p. 39). Successful aging is an individualistic model of aging, and emphasizes personal effort, decisions, and behaviors as key to fulfilling the criteria of successful aging. Based on this definition, people with dementia cannot be categorized as aging successfully. As Daffner (2010) posited, successful aging could even be defined as “eluding the development of dementia” (p. 1102). Hence, dementia serves, in a sense, as the antithesis of successful aging.

The normal, healthy, and successful aging paradigms each highlight the importance of maintaining health and able-bodiedness/able-mindedness (Gibbons, 2016). In doing so, they contribute to the medicalization of dementia by classifying disability as an individual “problem” that needs to be evaded to the greatest extent possible. Furthermore, such taxonomies place disabled elders, regardless of whether they aged with disability or aged into disability, in a class of “unhealthy” or “unsuccessful” agers (Rubinstein & de Medeiros, 2015). Hence, due to medicalization, people with dementia are largely excluded from the dominant paradigms of aging from within mainstream gerontology. Consequently, much of the research on dementia in mainstream gerontology focuses on behavioral interventions,

assessments of abilities using neuropsychological testing, long-term care, and the caregiving experience from the perspective of caregivers (Proctor, 2001).

However, as Bruens (2013) noted, the designation of dementia as a biomedical condition has resulted in "the collection of a large body of scientific knowledge and a substantial increase in research funding in Europe and North America, dedicated to understanding the causes of disease" (p. 81). Persons with dementia and their family and friends have strongly advocated for research that would lead to prevention, treatment, and eventually a cure for dementia (Activists Against Alzheimer's Network, 2016). While these desires are important to acknowledge, an exclusively biomedical approach and medicalization have resulted in dementia being understood solely in terms of loss (Beard et al., 2009). It has also contributed to the dehumanization of persons with dementia, as the disease is the focus over the person.

2. **Critical Gerontology**

Critical gerontology has critiqued much of the knowledge base in mainstream gerontology due to its alignment with the medical and natural sciences and its claim to produce "neutral" or "objective" knowledge about aging. Bass (2009) characterized critical gerontology as a broad category of scholars working in the areas of "political economy, moral economy, feminist theory, cumulative advantage/disadvantage, or structured dependency of aging" (p. 356). These perspectives share an emphasis on power, privilege, oppression, social structures, social inequalities, and social justice. Accordingly, Estes and Phillipson (2007) stated that the overall project of critical gerontology is "to provide alternative theoretical frameworks and emancipatory knowledge" (p. 330). Critical gerontology has thus produced important analyses related to aging and old age that mainstream gerontology has ignored or marginalized.

In regard to disability, critical gerontologists have challenged the dominant individualized and medicalized approaches within mainstream gerontology, many of which have been embraced by society. For example, critical gerontologists have critiqued healthy aging and successful aging in various ways. Many of these analyses cautioned against the individualized approach of the successful aging paradigm and noted that it was a medicalized view of aging that misrepresented aging as being in the control of individuals while ignoring social, economic, and cultural factors, including inequities related to class, gender, race, and other social locations (e.g., Clarke & Griffin, 2008; Dillaway & Brynes, 2009; Holstein & Minkler, 2003; Minkler, 1990). Several scholars also problematized that successful aging held the avoidance of disease and disability as "good aging" and the presence of disease and disability as "bad aging" (Holstein & Minkler, 2003; Minkler, 1990; Morell, 2003; Stone, 2003). Still others noted how successful aging promotes neoliberalism, which harms old and disabled people. As Martinson and Berridge (2015) explained, "By focusing the responsibility on individuals to maintain physical and cognitive function, the successful aging paradigm reflects and serves efforts to limit the state's responsibility to provide social and other supports for elders and people with disabilities" (p. 63). In other words, successful aging constructs old and disabled people's inability to age without disease or disability as "failure." Consequently, old and disabled people are blamed for their dependence and not seen as deserving of social and public supports (Gibbons, 2016).

This rejection of individualized and medicalized approaches to aging also applies to dementia. According to Baars and Phillipson (2013), critical gerontologists have argued that "the major problems that aging people encounter are not the inevitable result of biological senescence, nor of unfortunate decisions, but are constructed…through social institutions, and through the operation of economic and political forces" (p. 2). Hence, critical gerontology does not approach dementia as a medical condition, or as the result of an

individual's failure to engage in healthy and appropriate behaviors. Instead, it exposes the ways in which the experience of dementia, and old age, are socially constructed and culturally and socially situated (Harris, 2002).

Scholars within critical gerontology have also been instrumental in advocating for the inclusion of the perspectives of old people in gerontological research, including people with dementia (Innes, 2009). They have attempted to counter the exclusion of people with dementia by conducting research about the experiences of people with dementia and situating it within a socio-cultural context (Beard et al., 2009; Dupuis et al., 2012; Fetherstonhaugh et al., 2013; Proctor, 2001; Reid et al., 2001). Another key contribution of critical gerontologists is an emphasis on the concept of citizenship for people with dementia. Scholars working within this framework have argued that an emphasis on citizenship transforms the discourse on dementia from issues of self and personhood to rights, community and civic engagement, and social justice (Baldwin, 2008; Bartlett, 2014; Bartlett & O'Connor, 2010; Hulko, 2009). As Bartlett (2014) explained, people with dementia are:

> …becoming more influential in the public domain, speaking out, raising awareness, and participating in policy-making and implementation…Rather than passively accepting the tragic discourse of loss and demise typically associated with dementia, those directly affected by this condition are beginning to unite and seek opportunities to exert real influence in policy processes and society more generally. (p. 1293)

Consequently, a citizenship framework highlights the ways people with dementia are involved in communities and political processes. Furthermore, citizenship can also be used as a platform for advocating for the civil and human rights of people with dementia that they have historically been denied.

Overall, critical gerontology engages in important interventions regarding cultural and academic discourses of dementia by focusing on institutional and structural factors,

economic, political, and social contexts, inequalities, and social justice. At the same time, due to its emphasis on structural analysis, critical gerontology often fails to account for the ways in which aging and old age have individual and interpersonal meanings. As Baars and Phillipson (2013) noted:

> In spite of [critical gerontology's] justified critique of 'individualization', aging is also an existential process in which individuals and others in their life worlds are faced with major challenges against which structural mechanisms appear to be of little or direct relevance. And even if such structural mechanisms have created the problematic situations in which older people find themselves, it is usually not possible for them to wait for structural changes before resolving important issues affecting their lives. (p. 3)

In other words, critical gerontology does not account for individual or interpersonal meanings of later life, or consider existential issues related to aging, illness, and death. Furthermore, as Bass (2009) noted, much of the work within critical gerontology is situated in the social sciences. Consequently, although there are notable exceptions (e.g., Zeilig, 2013), some work within critical gerontology does not engage with key aspects of culture, such as language, philosophy, discourses, representations, and the media.

3. **Humanistic Gerontology and Aging Studies**

Whereas critical gerontology seeks to analyze structural factors of aging, humanistic gerontology and aging studies adopts an interpretative framework to explore aging at the individual, interpersonal, and cultural levels. As Baars and Phillipson (2013) observed, "Major crises that frequently take place in human aging, such as chronic illness…have to be faced by individuals…the confrontation with daily limitations and existential issues invites interpretations of the ways in which people experience aging" (p.

3). Generally, humanistic gerontology focuses more on examining aging at the individual and interpersonal levels, whereas aging studies engages in cultural analysis, yet both emphasize issues of meaning, discourse, and representation.

For dementia and other disabilities, scholars in humanistic gerontology and aging studies have adopted an approach similar to critical gerontology and advocated for the inclusion of people with dementia in research and scholarship. At the individual level, scholars in humanistic gerontology and aging studies have sought to explore how people with dementia make meaning of their experiences, and cope with the changes dementia may bring (Sabat, 2001). For instance, many scholars have focused on issues of identity and the concept of the self for people with dementia (Beard, 2004; Caddell & Clare, 2010; Hyden et al., 2014; Hughes, Louw, & Sabat, 2006; Moyle, Murfield, Venturo, Griffiths, & Grimbeek, 2013; Sabat, 2001). Much of this work argued that current conceptualizations of the self are normative and rely on hyper-cognitive ideals that exclude people with dementia. Further, they stated that people with dementia maintain a sense of identity and self. Such work is important to challenging dominant cultural discourses that people with dementia lack identity, a sense of self, and personhood.

At the interpersonal level, humanistic gerontologists have focused on the relational aspects of dementia, and how others may affect people with dementia (Harris, 2002; Hyden et al., 2014; Sabat, 2001). One of the most influential approaches to dementia that emerges from a humanistic framework is Kitwood's (1997) paradigm of person-centered care. Person-centered care shifted how people understood dementia by centering the person with dementia, versus focusing on dementia as a condition or the dementia "sufferer." Kitwood (1997) argued that persons with dementia are negatively affected by social processes such as infantilization and disempowerment, which he termed malignant social psychology.

Conversely, people with dementia are positively affected by person-centered and humanizing interactions.

At the cultural level, aging studies scholars have critiqued dominant cultural discourses and representations of people with dementia. For instance, Peel (2014) compared how dementia was represented in print media versus caregiver discourse. She found that the media contained two primary yet paradoxical frameworks, which she termed a “panic-blame” framework. One form of discourse catastrophized dementia and cast dementia as an uncontrollable epidemic. The other form focused on individual responsibility and implied people with dementia were to blame for their development of the condition. Conversely, caregivers engaged very little with these discourses, and seemed to be either unaware or resistant to them. Similarly, Behuniak (2011) explored popular and scholarly literature on dementia to uncover how people with dementia were cast as zombies, or the “living dead.” She argued that the zombie metaphor was based on disgust and terror, and contributed to a politics of fear and revulsion that led to the dehumanization of people with dementia. However, she also noted that recognizing the power of the zombie metaphor in cultural and scholarly discourse allows people to resist it by emphasizing connectedness, commonality, and interdependency. Such cultural analyses are essential to understanding the cultural and social contexts within which people with dementia live, and how dominant ideologies of dementia marginalize people with dementia.

Humanistic gerontology and aging studies have furthered understandings of dementia at the individual, interpersonal, and cultural levels, with a particular emphasis on issues related to meaning-making, representation, and discourse. However, there are also limitations to scholarship within humanistic gerontology and aging studies. Some work at the individual and interpersonal levels fails to consider broader economic, political, and social factors. Conversely, some work at the cultural level analyzes representations and

ideologies, but does not consider how people with dementia respond to or resist these dominant discourses. Furthermore, much of the work in humanistic gerontology attempts to challenge negative understandings of dementia by highlighting people with dementia's remaining abilities and capacities (Hyden et al., 2014; Sabat, 2001), without consideration for how such a strategy might marginalize people in advanced stages of dementia. Lastly, although there are some exceptions, scholarship that uses quantitative or qualitative methodologies to understand people with dementia's meaning-making processes or experiences focuses predominantly on people with dementia in the early stages, many of whom are community dwelling.

4. **Disability Studies**

Unlike mainstream gerontology, critical gerontology, humanistic gerontology, and aging studies, disability studies centers the study of disability from economic, political, cultural, and societal perspectives rather than the aging process or old age. In fact, generally speaking, disability studies scholars have been slow to engage with issues related to aging (Yoshizaki-Gibbons, 2018a). Priestley (2003) claimed that disability studies has been constructed within a generational system, which focuses on youth and middle-age and the roles associated with these life stages, such as education and employment.

Despite the fact that dementia is one of the leading causes of impairment for older adults, there is very little disability studies scholarship on dementia. Furthermore, much of the work that does use disability studies perspectives comes from scholars in critical gerontology and aging studies (Bartlett & O'Connor, 2010). One of the few disability studies frameworks that has been applied to people with dementia is the social model of disability (Bartlett & O'Connor, 2010; Gilliard et al., 2005). The social model of disability contrasts the medical model of disability by locating the problem of disability in society (Oliver, 2009).

Hence, the social model forwards that disability is socially constructed through prejudicial and discriminatory attitudinal, environmental, and structural barriers. In doing so, the social model distinguishes impairment—a functional limitation—from disability—a socially created system of oppression. This emphasis on disadvantages and restrictions caused by society has been used to organize for disability rights, including the rights for disabled people to live in the community, access public spaces and events, receive training and education, and work and earn a living wage (Llewellyn & Hogan, 2000; Wendell, 1996). However, in recent years, scholars in disability studies have sought to challenge and complicate the social model of disability (Meekosha & Shuttleworth, 2009), although dementia has not been explicitly considered in these analyses. Beyond the social model, there has been limited application of disability studies theories and frameworks to dementia. As Baldwin (2008) observes, “the disability model of dementia is still relatively under-theorized” (p. 223). Thus, it is important that disability studies scholars consider dementia and other issues related to aging and old age.

Disability studies has significant potential to transform how we understand dementia and treat people with dementia. As van Heumen (2012) argued, “Disability studies can provide valuable insights and applications in reframing dementia because of its social explanations of disability, emancipatory nature, aim to interrogate and change elements of the disabling world, and interdisciplinary approaches” (p. 109). Furthermore, engaging with dementia, and other issues of aging, also has the potential to further develop disability studies (Yoshizaki-Gibbons, 2018a). Dementia represents the ways age and disability are co-constructed, and thus serves as a site to examine how discourses and experiences of aging and disability intersect. Additionally, dementia can develop and complicate disability studies theories due to its implications for theorizing about issues such as memory, wordlessness, cognition, and selfhood. Relatedly, centering people with dementia pushes

disability studies to consider who is included and excluded from disability scholarship and activism.

C. Lived Experience of Dementia

Historically, little was known about the lived experience of dementia from the perspective of individuals with dementia. The majority of narratives have been produced by caregivers, researchers, and medical experts (Beard, 2004). Unfortunately, many individuals with dementia remain excluded from research. As Proctor (2001) lamented, “It is rare for the subjective experience of people with dementia to be considered, to be judged valid, possible to access, or worth listening to” (p. 362). However, there is a growing body of scholarship that explores the lived experience of dementia.

Much of this research highlights that Alzheimer’s disease and other dementias is a complex experience, which is best understood from the point of view of people with dementia (Sabat, 2001). As Harris (2002) asserted, “The voices of the real experts - the people who have been diagnosed with a dementing illness - are still muted, and although they may sometimes be heard, often they are not truly listened to” (p. xiii-xiv). Centering the perspectives of people with dementia provides new insights into how dementia is a social experience, rather than just a medical one. Such scholarship often utilizes person-centered (Kitwood, 1997), or social constructionist (Sabat, 2001) approaches. These paradigms for understanding dementia emphasize the ways in which dementia is socially created and maintained through prejudicial attitudes, discriminatory treatment, inaccessible environments, and dehumanizing cultural discourses. By exploring the ways in which dementia is socially constructed, people can work toward a society in which people with dementia’s humanity is respected.

1. The Identities of People with Dementia

A significant focus of this research considers how people with dementia understand, construct, and preserve their identities. A commonly held societal belief about dementia is that it results in an inevitable and inherent loss of the self. In her study of how people with dementia conceptualize their identities, Beard (2004) found that memory loss is not linked to a loss of identity or self. According to Beard (2004), “By engaging with people with [dementia], we see that identity construction is a deliberate, if shifting, accomplishment for people with dementia rather than simply an illness where self-identity increasingly vanishes. People with dementia manage to preserve a self” (p. 417). Thus, people with dementia engaged in various forms of identity management and preservation. Beard, Knauss, and Moyer (2009) built on this work by exploring how people with dementia managed the stigma of dementia in relation to their identities. They found that people with dementia consciously strive to incorporate a “manageable disability” into their existing identities. Using ethnography, Kontos (2006) advanced a theory of embodied selfhood to explore the ways selfhood is expressed through bodily movements, behaviors, clothing, and other manifestations of embodiment. Similarly, Hyden, Lindemann, and Brockmeier (2014) claimed that identity and self are part of the remaining agentive abilities of people with dementia and advocated for a new conceptualization of self which manifests in embodied expressions, emotional engagement, and social connection.

2. Subjective Experience of Dementia

Another important area of research on the subjective experience of people with dementia highlights the ways in which dementia is influenced by micro, meso, and macro elements. For instance, Harris (2008) draws from case studies of people with dementia who are living with dementia in personally meaningful ways, and argues that they

are resilient, which she describes as an adaptive process rather than a personality trait. She emphasized how a resilience paradigm takes into account individual, interpersonal, and structural determinants. In addition to exploring identity, Beard et al. (2009) analyzed the ways in which dementia is a social process. Participants emphasized issues with interactional, environmental, and structural factors. Negative interactional factors included being patronized, being coached, being over protected, being dismissed, and being excluded. Negative environmental factors included too much noise or other sensory stimuli and crowds. Negative structural factors included lack of access to transportation, lack of access to adequate healthcare, and lost income due to unemployment. By highlighting how many of the problems people with dementia experience are the result of social, environmental, and structural factors, Beard et al. (2009) drew attention to the ways in which dementia is socially constructed.

3. **People with Dementia's Experiences with Care**

Others have focused on people with dementia's experiences with care, particularly institutional long-term services and supports, such as nursing homes and residential facilities. Reid et al. (2001) explored the unmet needs of people with dementia in respite care and considered how they understood their role as service users. Participants expressed that they were people first, and that they had views, likes, and requirements for their care. Proctor (2001) examined how women with dementia felt about the care they were receiving and reported that the women wanted to be listened to and taken seriously by care providers. While this scholarship has made important contributions, none of this research centered the care relationships between institutionalized old people with dementia and their formal caregivers.

D. Theoretical Approaches to Care for People with Dementia

The term “care” may be used to describe an attitude, a value, a form of labor, and a relationship (Kittay, 2011). Care is a complex experience, particularly in the context of disability and aging. Within feminist and disability studies theoretical considerations of care, dementia is rarely considered. However, centering dementia in explorations of care provides an opportunity to expand the work of scholars seeking to bridge these fields and place them in conversation with each other (Berridge, 2012; Kelly, 2013). In this section, I discuss feminist ethics of care, disability studies theories of care, and gerontological theories of care.

1. Feminist Ethics of Care

Feminist ethics of care, also referred to as care ethics, are ethical theories that examine the moral values and actions that guide care. According to Kelly (2016), ethics of care “positions care as a moral framework grounded in the daily experiences of providing care” (p. 30). The ethics of care perspective emerged from the work of Gilligan (1982), who criticized Kohlberg’s stages of moral development, a dominant psychological theory at the time, due to its sole focus on boys and its assertation that girls mature more slowly than boys. Gilligan (1982) asserted that men and women tend to approach ethics differently. Men, who understand themselves in opposition to others, were more likely to use an ethic of justice in moral reasoning, which prizes rationality and fairness. Conversely, women, who understand themselves as linked to others rather than autonomous, were more likely to approach ethical decision-making using an ethic of care grounded in values such as empathy and compassion. Noddings (1984) further conceptualized ethics of care as relational—in other words, care occurs between a care provider and a care receiver. She also asserted care is not provided based on principles, but rather is based on the needs of

and responsibility for others. In these early theorizations of care, capacity for caring was forwarded as a strength. The social positioning of women as caregivers and the subsequent devaluation of caring and connection was criticized, and it was believed that both women and men should be taught to and expected to care.

Much of the early scholarship on care based on Gilligan and Nodding's work understood care as unpaid labor, occurring between women and non-disabled familial individuals (such as husbands or children). While this work was foundational to the theory of feminist care ethics, scholars and activists began to critique these early iterations of care ethics. They claimed that conceptualizing care solely as relational and dyadic limited political, social, and cultural analyses of care and dismissed society from the responsibility of providing care or approaching care as a human right (Erevelles, 2011; Kelly, 2016). In an important intervention, Tronto (1993) observed that an ethics of care based on the idea of "women's morality" does not grant women access to political, economic, and cultural power. Additionally, Tronto noted that the image of the "moral, caring woman" in the United States intentionally excluded women who were racialized, poor, immigrants, queer, or deemed "unfit" to be mothers. Thus, instead of attaching caring to women's morality, Tronto argued for including the values of caring—attentiveness, responsibility, nurturance, compassion, and meeting others' needs—in the United States' social and political order. This shift required politicizing care—in other words, understanding care as a public, rather than private, matter, and always occurring in relation to structures of power and inequality. Care is an issue in which people are agents, but also acted upon by social, cultural, and political forces. Understanding care as political uncovers the ways care exists within and perpetuates racialized, gendered, and classed exploitation. Hence, a social and political order that centers the values of caring would prioritize meeting people's needs for care over profit. Tronto (1993) ultimately forwards an ethic of care that acknowledges the reality that

all people need and receive care and give care to others—in fact, these caring relationships and interdependence are what marks us as human.

Tronto's work served as a starting point to critique the commodification of care in a capitalist society. Marxist feminists analyzed care as an outcome of gender divisions of labor and highlighted the ways in which care obligations and regulation to care work leads to the economic marginalization of women (Fraser, 1997; Okin,1989). Antiracist scholars and feminists of color furthered this critique by arguing that the politics of care are not only gendered, but also racialized and classed. According to Glenn (2010), "Women are charged with a triple status duty to care, on the basis of (1) kinship (wife, mother, daughter), (2) gender (as women), and (3) sometimes race/class (as members of a subordinate group" (p. 7). Throughout history, race, gender, and class have served as organizing principles of care work, and regulated women marginalized by race and class to low-paying, low-status work (Erevelles, 2011). Such theories of feminist ethics of care are important to understanding oppressive aspects of care, but often focus on care providers. In doing so, they ignore the experience and positionality of disabled people, including people with dementia. Conversely, disability studies scholarship and activism sought to center the disabled person in theoretical considerations of care.

2. **Disability Studies Theories of Care**

Within disability studies scholarship and activism, care was historically viewed as a form of oppression, and was thus rejected as a term and concept. As Kelly (2011) noted, "In the context of disability, care is haunted by the specters of institutionalization, medicalization and paternalistic charities which, in varying degrees past and present, systematically marginalize people with disabilities" (p. 564). Rather than advocate for care, disabled people called for personal support or personal care assistance that would maintain

their independence and autonomy. Early in the Disability Rights Movement, fueled by the social model of disability, disabled people began to critique social constructions of dependency, and challenged the dominant belief that disabled people were dependent due to functional limitations caused by their impairments (Shakespeare, 2014). According to Oliver (1989), dependency is "created amongst disabled people, not because of the effects of the functional limitations on their capacities for self-care, but because their lives are shaped by a variety of economic, political, and social forces which produces this dependency" (p. 17). These forces included attitudinal barriers, inaccessible environments, lack of access to essential resources, regulation to institutional care, and powerlessness (Charlton, 2000; Oliver, 2009).

Scholars and activists worked to challenge this structured dependency by demanding their independence and autonomy (also referred to as self-determination), which they connected to their right to community integration and social participation (Charlton, 2000). This strategy required disability studies scholars and activists to advocate for an expansion or reframing of the concepts of independence and autonomy. Dominant views construct independence and autonomy as being able to act alone and make decisions about one's life without assistance or interference from others. However, many disabled people in the Disability Rights and Independent Living Movements required various forms of support to live in community settings. Consequently, activists characterized independence as autonomy – independence was not completing self-care asks alone, but rather making decisions and directing how those self-care tasks were completed. The argument for autonomy and self-determination also applied to other areas, ranging from issues of personal preference (e.g., the location of one's home, how one's day is structured) to economic and political matters. As Charlton (2000) stated:

> [Self-help and self-determination] require people with disabilities to control all aspects of their collective experience. They simply mean: we are able to take responsibility for our own lives, and we do not need or want you to manage our affairs; we best understand what is best for us; we demand control of our own organizations and programs and influence over the government funding, public policy, and economic enterprises that directly affect us. (p. 128)

In other words, disabled people argued independence was defined by the ability to autonomously make one's own decisions and direct one's life, including the services and supports one received. As leader of the Independent Living Movement Judy Huemann explained, "To us, independence does not mean doing things physically alone. It means being able to make independent decisions. It is a mind process not contingent upon a normal body" (Kittay, 2011, p. 50). Thus, these scholars and activists attempted to reframe independence as something achievable for disabled people if they were provided with autonomy.

In doing so, they largely left the overarching concepts of independence and autonomy untouched and uncomplicated. As Wendell (1996) observed, "Far from questioning the high social value placed on 'independence,' early disability-rights movements sought more of it for their members (p. 146). However, this strategy had significant downsides. As several scholars and activists within feminist studies and disability studies have argued, the very concepts of independence and autonomy are problematic and oppressive because they uphold the myth of the "whole, independent, unified, self-making, and capable" subject (Davis, 2002, p. 26). It also creates a new ideal for disabled people: the "able disabled," who must deny vulnerabilities, limitations, weaknesses, and shame to maintain the façade of independence and autonomy (Wade, 1994). Furthermore, independence and autonomy can be used in oppressive ways by dominant societal

institutions (Zola, 1972). For instance, during deinstitutionalization, some states released disabled people into the community without proper support and described this move as increasing their “independence” (Wendell, 1996).

Dementia, particularly in the advanced stages, also challenges the Disability Rights and Independent Living Movements’ emphasis on independence and autonomy. By characterizing independence as a “process of the mind,” it excludes some people with dementia, as well as people with other mental disabilities, who may need support to make decisions and direct their own services, as well as those who are assumed to be incapable of doing so. As several disability studies scholars have observed, autonomy is based on the concept of a unified, rational self that is able to make informed and independent decisions (Nicki, 2001; Price, 2011; 2015; Siebers, 2008). This approach is highly exclusionary to people with dementia, who may present many different selves throughout the day and as their dementia progresses. Furthermore, depending on their memory and orientation during specific moments in time, they may be judged as highly irrational or incapacitated by others (Basting, 2005).

Thus, the claim that some disabled people can be independent further stigmatizes those who cannot, which is frequently people with various forms of mental disability, including people with intellectual and developmental disabilities, people with psychiatric disabilities, and people with dementia. As Wendell (1996) noted:

> The realization that ‘autonomy’ and ‘independence’ are unattainable goals for some people, even when they are defined in ways that take some kinds of disability into account, calls into question the value of these in any scheme of virtues and moral goals. (p. 149)

Hence, as exclusionary concepts, independence and autonomy are limited in their ability to ensure access to care and achieve social justice for all disabled people. Furthermore,

linking the concepts of independence and autonomy to community integration and social participation create a binary where independence and autonomy are associated with living in the community and dependence is associated with living in an institution. This strategy is unsurprising, since disability scholarship and activism approaches institutional care from an abolitionist perspective, with the goal of eliminating institutions (Chapman, Carey, & Ben-Moshe, 2014). However, elders are often excluded from such deinstitutionalization efforts. Furthermore, the emphasis on community living has resulted in little consideration of the ways independence and autonomy can be maintained to the fullest extent possible in institutional settings, such as nursing homes (Boyle, 2008). This issue particularly affects people in the middle or advanced stages of dementia, who are more likely to receive care in nursing homes due to the unavailability of community services and supports that are able to fully meet their needs.

To address some of these issues with independence and autonomy, disability studies scholars and activists shifted their emphasis to interdependence. Interdependence highlights the ways in which all humans, disabled and non-disabled, rely on others in various forms and are dependent on others in a multitude of ways. As Garland-Thomson (2011) noted, “Disability itself demands that human interdependence and the universal need for assistance be figured into our dialogues about rights and subjectivity” (pp. 29-30). Over time, this emphasis on interdependence grew stronger and has become a key value within disability scholarship, culture, and activism (Hamraie, 2013; Kafer, 2013; Longmore, 2003; Patsavas, 2014; Price, 2015; Wendell, 1996).

However, dementia challenges interdependency in significant ways. Interdependency implies a reciprocal relationship in which each person shares the responsibilities of providing support and care. Although each participant may rely on and be responsible for the other in different ways that change over time, there is still a sense of

mutuality guiding the interdependent relationship. Consequently, some scholars in disability studies have begun to challenge the value of the concept of interdependency, although not within the context of dementia. For instance, feminist scholars have critiqued the ways in which interdependence is universally cherished within disability studies and other areas, noting that it may marginalize women with histories of abuse and trauma (Donner, 1997; Nicki, 2001). Discourses promoting interdependence often assume every person is capable of connection, interaction, and care of others.

Furthermore, even when it is recognized that an interdependent relationship may not be between relative equals, there is still the expectation that both parties will contribute in some way. As Wendell (1996) noted, “Relationships of reciprocity are not necessarily equal…in that one person may give more care, or have more responsibility for providing care, than another. Nevertheless, they involve moral obligations on both sides” (p. 150). For people with dementia, particularly advanced dementia, they may not be able to contribute to others in ways that align with societal norms regarding reciprocity. In fact, some depict dementia as a process of increasing dependency, and people with dementia in the later stages may become totally dependent on others for care (Volicer, 2005). Consequently, people with dementia engage in complex relationships with family, friends, and paid care partners, that are at least partly characterized by dependency (Basting, 2009).

Kittay (2011) drew from her experience caring for her daughter with an intellectual and developmental disability to claim that dependent persons can still enter into reciprocal relationships. She called attention to “the extraordinary possibilities inherent in relationships of care toward one who reciprocates, but not in the same coin; one who cannot be independent, but makes a gift of her joy and love” (Kittay, 2011, p. 57). Hence, according to Kittay, such relationships are still characterized by interdependence, but due to their affective value. However, people with dementia may not be able to consistently

demonstrate joy and love. Due to memory loss, disorientation, and confusion, people with dementia often express sadness, frustration, anger, and even aggression and violence when a person is trying to care for them. While these emotions and actions certainly do not make them any less deserving of care, as all humans share these affective experiences, they do challenge the idealized view that dependent persons provide their care partners with a consistent source of joy and love.

Erevelles (2011) further complicated this argument by noting that an emphasis on the emotional aspects of care provision as a form of reciprocity does not acknowledge the material contexts in which people provide care in an era of translational capitalism. She wrote:

> Affective labor…envisions an ethics of encounter that transcends the problematic inequalities that might arise as a result of these intercorporeal encounters between caregiver and care recipient. Affective needs can be met only if basic needs are met. In the current economic context…we know that families continue to struggle to meet their basic needs. It is in the context of these struggles to meet basic needs that the caring work for disabled people becomes an undue burden. (Erevelles, 2011, p. 194)

Thus, interdependence assumes an equality between care recipient and care provider that does not exist for marginalized people in the context of social oppression, and affective value is inadequate when people are trying to survive.

Consequently, Erevelles (2011) and Price (2015) argued for a materialist feminist disability studies ethic of care, which foregrounds the caregiver and the care recipient and considers how these roles position them. Erevelles (2011) stated, “We need to foreground the material conditions of transnational capitalism that enable the specific relations of production and consumption that construct social difference in order to transform the body politic” (p. 197). Accordingly, rather than theorize about care in the context of dependency

and work to construct such relationships as interdependent, disability studies scholars and activists can work toward interdependency by advocating for socially just conditions for those in care relationships. Dementia care in nursing homes serves as just one potential site for this type of scholarship and activism.

Like Erevelles (2011) and Price (2015), Kelly (2011) sought to address the gaps in feminist and disability studies' theoretical approaches to care through her framework of "accessible care." Accessible care intends to draw attention to the paradoxical nature of care and promote a multi-layered definition of care that captures its complexities. According to Kelly (2011), care "represents the failure of medical cure and neoliberal progress; it is a deep compassion and empathy; a highly intimate relationship; an institutionalized approach to disability; a transnational supply and demand of feminized labor; a dependency on state-funded programs" (p. 790). Rather than focus on these aspects of care singularly, accessible care seeks to recognize these convoluted, and at times conflicting, experiences of and discourses surrounding care. Thus, accessible care "is an unstable tension among emotions, actions, and values, simultaneously pulled toward both empowerment and coercion" (Kelly, 2013, p. 790). Kelly (2013) used the term accessible to highlight the ways that care, like access, is connected to cultural discourse, built and material environments, and social inequalities. Understanding these linkages provides insights into how society can intervene in issues of care to continuously move toward the goal of accessible care.

3. **Gerontological Theories of Care**

Within gerontology, much of the research on care utilizes medical and welfare-based perspectives and is focused on practical aspects of providing and improving care. Care scholarship often focuses on interpersonal relationships, caregiver burden and satisfaction, care management, and elder abuse (Twigg, 2000). Consequently, as Berridge

(2012) noted, “Care is under-theorized in gerontology” (p. 10). Williams and Busby (2000) further observe that, from a disability studies perspective, gerontological knowledge on care lacks structural and political analyses. Hence, theories of care within gerontology often focus on individual experiences and interpersonal interactions.

One of the most significant contributions to dementia care is Kitwood’s (1997) framework of person-centered care. Kitwood (1997) observed that within dementia care, the personhood of individuals with dementia is often undermined by caregiver behaviors, such as outpacing, ignoring, infantilizing, manipulation, and invalidation. These behaviors result in “malignant social psychology,” which Kitwood (1997) argued led to the dehumanization of people with dementia. Person-centered care is a humanistic and psychosocial approach that works to resist medicalization and depersonalization by shifting the focus from “the dementia sufferer” to “the person with dementia” (Bruens, 2013). Person-centered care requires recognizing people with dementia as individuals, and tailoring their care to recognize their unique personality, preferences, desires, and needs. In doing so, caregivers can accord personhood to people with dementia through humanizing interactions that emphasize independence, autonomy, respect, and dignity.

Additionally, person-centered care encourages caregivers to view relationships with people with dementia as mutual and reciprocal. According to McIntyre (2003):

> In the context of dementia, we often forget that relationships are still a two-way street...We can forget mutuality and reciprocity—we sometimes only notice what needs to be done, the symptoms and physical manifestations of the illness—and fail to notice or be with the person. (p. 479)

Rather than approach care as a one-way interaction, person-centered care conceptualizes care as relational and occurring between individuals.

Person-centered care has flourished, with numerous models emerging from the theory that have improved care for people with dementia (Bruens, 2013). For example, one approach to enacting person-centered care is dementia care mapping, which involves a person (the mapper) observing people with dementia in communal settings of care facilities and recording the behaviors, mood, and engagement of the person with dementia over time and rating the interactions between the person with dementia and care staff (Brooker, 2005). These data are then used to develop a care plan for the persons observed that is specific to them as individuals and will improve their well-being and quality of care. Such models are key to ensuring person-centered care is assessed and practiced in long-term care settings.

Person-centered care has also been written into policy, with federal guidelines requiring long-term care facilities to provide person-centered care. The Nursing Home Reform Act of 1987 included a regulation that every nursing home resident must "be provided with services sufficient to attain and maintain his or her highest practicable physical, mental, and psychosocial well-being" (OBRA 42 CFR 483.30). This policy was viewed as an early implementation of person-centered care requirements (Koren, 2010). Since then, person-centered care has been written into additional legislation and required more broadly throughout the healthcare system. According to the Agency for Healthcare Research and Quality (2016), "The Affordable Care Act's (ACA's) repeated references to patient satisfaction, engagement, and shared decision-making cemented the idea of patient-centered care as a key component in the delivery of quality health care in the United States" (para 5). In 2017, new regulations established by the Centers for Medicare and Medicaid Services went into effect that defined person-centered care and outlined rules that nursing homes must follow as part of providing person-centered care (Bowman, 2017). Such

policies have transitioned person-centered care from an exalted theory and practice to a mandate.

However, there are still limitations to person-centered care. Nationally, many nursing homes espouse their commitment to person-centered care and report meeting the guidelines established by CMS, yet practice the principles of person-centered care to varying degrees. As Bruens (2013) noted, “The gap between ideal and actual care for people with dementia is still considerable, with evidence for continuing stigmatisation” (p. 81). Hence, there is a gap between theory and practice of person-centered care. Furthermore, the theory of person-centered care centers on individuals in their microenvironment. This conceptualization situates care at the interpersonal level. As a result, problematic aspects of care are often discussed without attention to contributing cultural or societal factors. For example, Sabat (2001) highlighted the issues that arise out of malignant social psychology, but also provided the caveat:

> Of course, no caregiver would intentionally inflict such potentially devastating treatment on a loved one or client. Thus, we can understand such behavior more accurately as being rather “innocent” and not springing from ill-will, for the situations facing caregivers are often daunting and exhausting. (p. 97)

Sabat (2001) continued that malignant social psychology thus results from the ways people with dementia are positioned in care contexts. While it is important to address dehumanization and violence at the individual and interpersonal levels, such as an approach ignores the systemic causes of violence. Person-centered care does not consider how socio-political factors influence the culture of care within long-term care facilities (Bruens, 2013). Such factors may include dominant societal views that characterize dementia as a dehumanizing illness, and how people with dementia experience ageism and ableism and other forms of social inequality. This lack of attention to structural issues and

social locations limits analyses of care that seek to intervene culturally, economically, and politically.

Furthermore, Twigg (2004) noted that dominant conceptions of personhood in Western societies exclude people who need care. Rather, disabled old people are reduced to their bodies - bodies that require care. Noting the qualitative distinction between the third age, a time of leisure, consumerism, and personal fulfillment, and the fourth age, a time of infirmity and increasing dependency, Twigg claims that the body is central to experiences of ageism, particularly in deep old age. She also highlighted the ways in which this experience is gendered, as the bodies of women in deep old age require care, often by others. While Twigg only mentions dementia as one way people experience the fourth age, her work emphasized the ways that gerontology must contend with issues of the body as culturally, politically, and socially constructed, particularly within the context of care, rather than just exulting personhood.

However, a growing body of scholarship within gerontology seeks to apply citizenship, human rights, and social justice frameworks to dementia and dementia care. A citizenship perspective seeks to move beyond personhood by framing people with dementia as active social agents (Bartlett & O'Connor, 2010). In doing so, it shifts the focus to "social, political, and cultural dynamics rather than individual clinical or social psychology" (Bartlett & O'Connor, 2010, p. 4). Furthermore, the paradigm of citizenship can be used to procure rights and entitlements for people with dementia, such as inclusion in the labor force, access to state-provided social provisions like healthcare and income security, and participation in society (Bartlett, 2014; Bartlett & O'Connor, 2010; Brannelly, 2011). Within the context of care, a citizenship perspective has been applied to call for changes in practitioners' values and attitudes (Brannelly, 2011), advocate for a human-rights based culture of care (Kelly & Innes, 2013), and campaign for policy changes that ensure people

with dementia in institutions are provided with rights that support their autonomy (Boyle, 2008).

Building on citizenship and social justice perspectives, Behuniak (2010) argued for a political model of dementia that seeks to understand the meaning of power in the context of dementia care. Behuniak (2010) argued that although personhood has dominated gerontological care literature, legal understandings of personhood still exclude people with dementia. Political approaches to dementia can address this issue by viewing people with dementia as "vulnerable persons who are entitled to compassionate uses of power that ensure both legal rights and protections" (Behuniak, 2010, p. 232). Behuniak (2010) challenged traditional understandings of protections by claiming that such laws would not protect people with dementia from themselves, but rather protect their right to participate in decision-making and enact autonomy in their own care.

Berridge (2012) called for a gerontology-enriched theory of care by integrating Nussbaum's (2007) capabilities approach with feminist care ethics and disability studies theories of human rights. Nussbaum (2007) argued that a capabilities approach consists of basic entitlements that comprise "a life that is worthy of human dignity" (p. 155). The capabilities include: (a) life; (b) bodily health; (c) bodily integrity; (d) sense, imagination, and thought; (e) emotions and attachments; (f) practical reasoning; (g) affiliation with other humans; (h) relation to nature and animals; (i) play; and (j) political and material control over one's environment. Nussbaum (2007) contended that just societies should support all these capabilities using an outcome-based approach.

Berridge (2012) highlighted that drawing from a capabilities approach would benefit gerontology in three ways. First, adopting a human rights framework would better position gerontologists to build coalitions with disability studies scholars and activists. Second, the capabilities approach moves away from traditional gerontological understandings of

dependency, framed by activities of daily living, toward a justice paradigm that requires elders have opportunity to direct their own lives and be respected as citizens. Third, the capabilities approach allows gerontologists to simultaneously critique injustices related to elders' unmet needs and the oppression of those who provide care. As Berridge (2012) explained, "Paired with a relevant theory of justice, contributions to theories of care that are built on knowledge of both sides of the relationship have the greatest potential to bring care theory into cooperation with disability theory and gerontology" (p. 18). Thus, similar to Kelly's (2011, 2013) framework of accessible care, a gerontology-enriched theory of care seeks to go beyond approaches to care that view it as an individual need or relationship and also frame it as a human rights and social justice issue.

E. **Dementia Care in Long-Term Care/Institutional Contexts**

The majority of people with dementia receive care through long-term services and supports (LTSS). LTSS are an essential aspect of care for aged and disabled individuals. According to Reaves and Musemeci (2015), LTSS "encompasses the broad range of paid and unpaid medical and personal care assistance that people may need—for several weeks, months, or years—when they experience difficulty completing self-care tasks as a result of aging, chronic illness, or disability" (para 2). Unlike acute care, which is intended to be short-term and usually occurs in settings like hospitals, LTSS are provided for an extended period of time. Generally, LTSS provides assistance with two categories of self-care tasks: Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). ADLs are basic tasks, such as eating, bathing, dressing, toileting, walking, and continence. Conversely, IADLs are more complex tasks necessary for independent living, such as shopping, preparing meals, housework, and managing finances. LTSS can also provide housing assistance and support to family caregivers. The services provided under

LTSS are diverse, and include nursing home care, adult day service programs, home health aides, personal care attendants, and transportation. (Reaves & Musemeci, 2015).

1. **Service Delivery Funding**

Overall, LTSS are expensive. Home and community-based services are more affordable than institutional care, but LTSS beneficiaries and their families are often unable to finance care in either setting. As Reaves and Musemeci (2015) noted, “Beyond unpaid care provided by relatives, LTSS costs often exceed what individuals and families can afford given other personal and household expenses” (para 7). As a result, the majority of LTSS are financed through public health insurance programs, such as Medicare and Medicaid, with Medicaid serving as the primary payer for both institutional and community-based LTSS.

2. **Settings of Long-Term Supports and Services**

LTSS are provided in two primary locations: home and community-based settings and institutional settings. Home and community-based settings refer to personal residences, such as homes and apartments, and group homes, which typically house between 4—16 individuals, whereas institutional settings refer to care facilities such as nursing homes and residential care facilities.[10] Over the past twenty years, advocacy work and policy reform has focused on rebalancing LTSS away from institutional care toward home and community-based services. A variety of factors has contributed to these efforts. As Putnam, Pickard, Rodriguez, and Shear (2010) noted:

[10] Within disability studies, many scholars and activists argue that group homes are institutions. The National Council on Disability (2012) defined institutional settings as housing in which more than 4 disabled people live in a single home or space, and Self Advocates Becoming Empowered defined institutions as “any place, facility, or program where people don’t have control over their lives”. Chapman, Carey, and Ben-Moshe (2014) suggested that institutionalization may be conceptualized as spaces in which there are practices of power and domination, as well as resistance and negotiation, between consumers, clients, confined people, and staff. However, under federal LTSS guidelines, group homes are considered community-based settings.

> Spurred by economic realities, a sense of social justice, and a recognition of the family-centered nature of caregiving, federal and state-policy discourse now includes regular discussion of avoiding unnecessary nursing home placement and increasing consumer choice and control in community-based services. (p. 174)

For example, in 1999, the Supreme Court decided in *Olmstead v. L.C.* that people with disabilities have the right to receive services and care "in the most integrated setting appropriate" to their needs (Olmstead v. L.C., 1999).

Additionally, the Medicaid Home and Community-Based Services Waiver (HCBS) allows states to waive certain Medicaid requirements and receive federal Medicaid cost sharing in order to pay for non-institutional services (Heller & Schindler, 2009). Such policies have had a profound impact on LTSS service delivery settings. For instance, Medicaid funding for HBCS doubled between 1995 and 2011, and is growing much more rapidly than spending on institutional care (Shih et al., 2014). Nationally, by 2014, 53% of all Medicaid long-term care spending was on home and community-based services (Ng et al., 2016). Presently, the majority of people with dementia receive care in home and community-based settings. However, as previously discussed, dementia places many older adults at risk for institutionalization (Alzheimer's Association, 2020a). According to Accius and Flinn (2017), old and disabled people "are still disproportionately served in nursing facility settings" (p. 2). Furthermore, states vary widely in their implementation of HCBS, and many states—including Illinois—have long wait lists for their HCBS Waivers but no wait lists for nursing home care, thereby creating an institutional bias that affects old disabled people, particularly those with dementia (Dernbach, 2019).

3. **Care Providers**

LTSS are supplied by informal and formal care providers. Informal care providers are unpaid, and typically are family members, friends, or neighbors. As Shih et al. (2014) stated, “The vast majority of LTSS…are provided by informal caregivers: as much as 80 percent” (p. xii). According to the Alzheimer’s Association (2020a), approximately 16 million people in the United States are informal caregivers to people with dementia. Additionally, informal care providers often continue involvement with their loved ones even when formal care providers are used. As Heller and Schindler (2009) observed:

> Family members often provide informal support including both social-emotional and instrumental support that complements or even supplements the formal supports available. These informal supports are invaluable to these individuals, since they are related to higher morale, decreased loneliness and worry, feelings of usefulness, lower mortality, better survival and recovery from acute conditions, and reduced institutionalization. (p. 301)

Consequently, even when formal supports are used, informal caregivers are essential to the LTSS system.

Informal care providers face significant challenges related to caregiving, particularly since many engage in care without payment or adequate supports. According to Gitlin and Hodgson (2015), dementia caregivers commit more time to caregiving, have greater care responsibilities, experience more financial burdens, and report more stress and emotional distress than the caregivers of elders without mental disabilities. Although a number of effective dementia caregiving interventions that support caregivers have been designed, these are often not widely translated into practice (Gitlin et al., 2015). The lack of support for informal caregivers places elders with dementia at a greater risk for institutionalization.

Unlike informal caregivers, formal care providers, also referred to as direct care workers, are paid employees, such as nurses, home health aides, and personal care assistants. In nursing homes, the majority of staff who work with elders with cognitive impairments are certified nursing assistants (CNAs). CNAs are predominantly women, many of whom are marginalized by race, ethnicity, class, and immigrant status (Allen & Cherry, 2005; Khatutsky et al., 2011; Paraprofessional Health Institute, 2019; Wellin, 2018). CNAs support residents with ADLs and IADLs, such as bathing, dressing, eating, and housekeeping.

Within nursing homes, CNAs and other direct care workers are critically important to the well-being of residents with dementia. Research has demonstrated that the attitudes, stress, and satisfaction of direct care workers influences care and resident quality of life. In regard to care, Zimmerman et al. (2005b) found that staff with less experience (i.e., approximately 1-2 years) reported more stress, but were more likely than long-term staff to espouse person-centered attitudes toward providing care for people with dementia. Furthermore, person-centered attitudes were associated with perceived increased competence in providing care and work satisfaction. Within the realm of quality of life, Zimmerman et al. (2005a) found that people with dementia experienced a higher quality of life when they resided in nursing homes that encouraged activity participation, trained staff in domains important to dementia care, and specifically assigned these highly trained staff to dementia care. Engaging staff in care planning, working with staff with person-centered attitudes, and supporting communication between residents and staff also led to higher quality of life. Such research demonstrates the importance of attending to direct care worker's well-being.

However, direct care workers face many challenges in their work, including lack of adequate training, low pay, and lack of benefits (Alzheimer's Association, 2020a;

Paraprofessional Health Institute, 2019, 2020). Training is a huge issue within the direct care workforce. As Shih et al. (2014) noted, “Inadequate training for dementia in the direct care workforce has been identified as a main contributor to poor quality of life, poor quality of care, abuse, and neglect in nursing homes” (p. xiii). Direct care workers benefit from training that is specific to dementia, and includes topics such as the stages of dementia, communicating and interacting with people with dementia, person-centered care, and end of life care (Meeks et al., 2018). It is also important that staff receive regular and ongoing training (Zimmerman et al., 2005b). Additionally, Dupuis et al. (2012) argued that training for direct care workers must be person-centered. In their study of staff’s interpretations the behaviors of people with dementia, they discovered that staff viewed resident behaviors through a lens of pathology, which resulted in them characterizing the behaviors as challenging and responding through crisis management, rather than seeking to understand the meaning behind the behaviors and valuing the experiences of people with dementia.

Another significant issue is the lack of economic support for direct care workers. Nationally, the median pay in 2019 for CNAs was $29,640 (Bureau of Labor Statistics, 2020). Within Illinois, the Service Employees International Union (2007) reported, “Illinois’ nursing home owners further cut costs by paying extremely low wages to their front-line caregivers. Most caregivers’ wages are so low they can’t afford market rate housing” (p. 5). Based on the average wages of certified nursing aides, housekeepers, and cooks in nursing homes, Service Employees International Union (2007) found that direct care workers were hovering at the federal poverty line for a family of four and were thus eligible for food assistance and public housing assistance. Relatedly, many CNAs were denied access to benefits such as paid leave, health insurance, disability insurance, and retirement benefits. Low wages and lack of benefits may result in higher levels of stress and lowered job satisfaction. The denial of fair wages for direct care workers has been connected to high

turnover rates, which results in a less stable, highly qualified, and well-trained workforce (Shih et al., 2014). Given that many direct care workers are also women, and increasingly immigrant women of color, this lack of economic support contributes to their marginalization (Allen & Cherry, 2005; Khatutsky et al., 2011).

The landscape of dementia care is incredibly complex. Whether care is provided in the community or in institutional settings, people with dementia and those who care for them often lack access to financial, educational, emotional, and community supports, which contributes to their vulnerability. Within institutional care specifically, insufficient pay and benefits, inadequate training, complex bureaucracy, and difficult labor affect care providers negatively and influence the quality of care for people with dementia.

F. **The Culture of Dementia and Institutional Long-Term Care**

A nursing home is simultaneously a home, a health care organization, an institution, a place of employment, a regulated industry, and a for-profit or non-profit business. As each of these roles have distinct and frequently opposing purposes, foundational beliefs, and outcomes, a nursing home is “a center of contradiction” (McLean, 2007, p. 62). Consequently, a nursing homes has a unique cultural context. At the same time, a nursing home represents and reinforces the larger society in which it is situated. As noted by McLean (2007), “It shares and reproduces some of the larger cultural assumptions about aging, the elderly, and their needs; it is thus a product of the social, political, and economic system of which it is a part” (p. 61). As such, understanding the distinctive cultures of nursing homes uncovers how society approaches important aspects of life, including aging, disability, and care.

There have been several important ethnographic explorations of nursing homes that have contributed to understanding daily life in a nursing home and the diverse experiences

of nursing home residents, their family members, direct care workers, and administrators. Gubrium's (1975) work, *Living and Dying at Murray Manor*, is a foundational ethnographic text that examines how care is organized in a nursing home in the United States. Gubrium discusses how nursing homes are singular organizations yet consist of different and at times colliding worlds—the world of the administration, the world of the care staff, and the world of the nursing home residents, and the world of the families. These conflicting worlds led to complications in the nursing home's operation. For instance, the administration strongly forwarded the goal of high-quality care, but without an understanding of how care actually worked in practice on the floor. Conversely, due to various staffing and organizational restraints, the care staff's goal was "just getting the job done." The residents, meanwhile, understood a major aspect of care as connecting and spending time with care staff, which the care staff tried to oblige but often experienced these moments as taking time away from their required duties. Gubrium highlights these complexities throughout his project, emphasizing the ways that the distinct worlds of the participants influence their experiences in Murray Manor.

In *Uneasy Endings: Daily Life in an American Nursing Home*, Shield (1988) conducted an ethnography of Franklin Nursing Home, a highly rated non-profit nursing home, for 14 months. Shield found that living and working in a nursing home was characterized by uneasiness. Specifically, the residents were uneasy in the liminal space between their previous role in the community and their role in an institution. They also experienced uneasiness in their transition from adulthood to death, as there was no cultural rituals or community support available to them for this rite of passage. Lastly, the residents were also uneasy with their increasing dependency. Shield discovered that there were barriers that prevented the residents from engaging in reciprocal relationships with the staff, deepening their reliance on the care staff.

Gubrium's (1975) and Shields' (1988) explorations of the complexities of living, working, and dying in a nursing home shaped a developing research genre focused on the sociology of nursing homes. Savishinsky (1991) explored the ways staff and residents engaged in storytelling to make meaning of their experiences. Diamond (1992) focused on the certified nursing assistants and orderlies in nursing homes, highlighting the ways they managed to care for the residents while navigating low wages, family obligations, and other external pressures. Forner (1994) also focused on certified nursing assistants, examining how they derive meaning from the culture of their work which allows them to adapt to their jobs. In *Gray Areas: Ethnographic Encounters with Nursing Home Culture*, Stafford (2003) presents a collection of nursing home ethnographies, with each chapter focusing on a specific aspect of nursing home culture, such as meaning making, treatment of illnesses, food, and family involvement and relationships. Rodriguez (2014) examined the differences between the operation of a non-profit nursing home and a for-profit nursing home in *Labors of Love: Nursing Homes and the Structures of Care Work.* He uncovered the inner workings of each nursing home, and the challenges they faced in terms of funding, administrative regulations of Medicaid and Medicare, relationships between administration and care staff, and the care staff's struggle to provide high quality care while being overworked and underpaid. Despite these challenges, Rodriguez also notes that many ways nursing home workers make meaning out of the structures of care work by connecting and building relationships with residents.

Each of the ethnographies discussed thus far focused broadly on the nursing home, but there have also been several ethnographies that specifically focus on residents with dementia and dementia units. McLean (2007) examined two distinct dementia units – one which used a biomedical approach to dementia and sought to "control" "disturbed" behaviors and one which used a person-centered philosophy of care that understood

behaviors in context as forms of communication. Residents with dementia in the biomedically-oriented unit experienced more significant decline, whereas residents with dementia in the person-centered unit experienced stability and, at times, improvement. McLean's (2007) findings indicate the importance of philosophies of care within dementia units and nursing homes in general.

The (2008) conducted an ethnography in a nursing home in the Netherlands, specifically focusing on death and end-of-life issues. The argued that the deaths of residents with dementia are hidden away, invisible to much of society. At the end of life, complex issues arose including the decision to stop treatment, tensions between white, wealthy family members and black, poor care workers, voodoo rituals enacted by the care staff at the end of life, and the difficult process of "letting go" of loved ones with dementia.

Jaffe and Wellin (2008) told the narrative of a resident with dementia, June, based on their ethnographic fieldwork of a residential care center for people who had been diagnosed with dementia. They documented June's difficult transition to residential care, noting the many ways that June resisted being treated as a compliant object of care by the staff, which in turn, caused the care staff to try and control her even more and even blame her for the issues she was experiencing. Jaffe and Wellin noted that the story of dementia has historically been based on the stories of caregivers—and thus the story has become one of grief, loss, frustration, exhaustion, and stress. In June's story they found alternatives to this narrative, such as struggle, hope and strength.

Leibing and Cohen's (2006) edited collection*, Thinking about Dementia: Culture, Loss, and the Anthropology of Senility,* contains numerous ethnographic explorations of dementia, several of which occurred in dementia units and nursing homes. McLean (2006) specifically focused on residents with dementia labeled as having "seriously disturbed behaviors," with the goal of examining the contexts in which the behaviors occurred,

evolved, escalated, or resolved and noting the ways that such behaviors were failed efforts at communicating rather than symptoms of brain deterioration. Kontos (2006) examined personhood in residents with dementia in a nursing home in Canada, using the theory of embodied selfhood to challenge the idea that people with dementia lack selfhood. Drawing on participant observation of people with dementia, she argued that the body is the means by which people with dementia communicate with the world and that the body itself is a source of selfhood not dependent on cognitive forms of knowledge.

Since Gubrium's seminal work in 1975, the genre of ethnographic nursing home research has expanded significantly and increasingly diversified. This body of research has focused on the worlds of people living, working, caring, and dying in nursing homes—spaces that are often ignored and avoided due to larger cultural discourses around aging, death, and institutionalization. Through ethnography, cultural and social understandings of dementia, caregiving, dementia units, and nursing homes have deepened, providing a glimpse into the daily lives of residents, care staff, administrators, and families who are too often out of sight, out of mind.

G. **Dementia, Dementia Care, and Social Location**

Social locations refer to the social groups people belong to due to their position in history, culture, and society. The social location of individuals is determined by gender, race, class, age, disability, sexuality, religion, and geographic region. Social locations are complex constructions which influence our identities, culture, and experiences of power, privilege, and oppression. Black feminist theories such as the matrix of domination (Collins, 2009) and intersectionality (Crenshaw, 1991), have highlighted the ways that social locations intersect and form interlocking systems of oppression. Much of the existing research on dementia and dementia care has not explored social location, and often

presents “people with dementia” as a homogenous, unified group (O’Connor et al., 2010). In doing so, it fails to place dementia within a broader sociocultural context and engage with the ways that dementia is a gendered, classed, and racialized experience (Bartlett & O’Connor, 2010; Hulko, 2009).

The limited research that does focus on social location often does so through the examination of dementia’s connection to a particular social identity, such as race, ethnicity, or gender. For example, Proctor (2001) examined the experiences of women with dementia, highlighting the ways in which they were subjected to sexist and ageist attitudes within care and oppressed across axes of age, gender, and disability. Proctor (2001) used the women with dementia’s stories to listen for psychological and political resistance to this subjugation. Forbat (2003) explored the ways in which willful neglect and institutional racism prevented people of color with dementia and their families from accessing services and supports. O’Connor et al. (2010) emphasized such research is an important starting point but called for more intersectional analyses of social location in regard to dementia.

Hulko (2009) engaged in an intersectional analysis of the experiences of people with dementia, some of whom were multiply privileged and some of whom were multiply marginalized. She argued that the people with dementia who had experienced prejudice and discrimination throughout the life course due to racialization, gender expression, or socioeconomic status, had developed resilience in the face of structural oppression and were able to apply that to their experience with dementia. O’Connor et al. (2010) also used intersectionality to analyze how one woman’s position as middle-aged, aboriginal, queer, and poor constructed her experience of dementia. They found that their participant, Betty, drew on her aboriginal background to reject biomedical discourses of dementia and define her experience of dementia as one of creativity and growth in addition to loss. At the same

time, Betty's sexuality, age, and socioeconomic status often rendered her invisible to others and limited her support. According to O'Connor et al. (2010), this story demonstrates:

> the fluidity and complexity associated with making sense of, and responding to, dementia by drawing on diverse social positions that that are constantly in flux, interactionally grounded, and continuously reconstituting one another, simultaneously creating varying degrees of advantage and disadvantage. (p. 38)

Hence, studies involving people with dementia must go beyond their positionality as "old" or "ill," and consider how constructions of age, disability, race, class, gender, sexuality, and immigrant status influence their experiences.

H. Gaps in Understanding Lived Experiences and Care Relationships in Institutional Contexts

One consequence of the biomedicalization of dementia is that people with dementia were not believed to be reliable narrators of their own experience. However, due to the emergence and popularization of person-first perspectives and person-centered care, people with dementia are increasingly included in research. Despite this, many people with dementia continue to be excluded. When people with dementia are included in research, they are frequently in the early stages of dementia, are community dwelling, and are privileged across axes of gender, race, class, religion, and sexual orientation (Hulko, 200). As noted by Bartlett and O'Connor (2010), "There is very little gendered or socioeconomic analysis of people's experiences of dementia. With few exceptions, social location, with its attendant privilege and disadvantage, is rarely incorporated into the discussion" (p. 6). Thus, there is a need to engage in research that centers women with dementia who are multiply marginalized and experiencing institutionalization.

Additionally, much of the current literature on dementia does not approach dementia as a disability or does so in a way that risks further marginalizing people with dementia with more significant impairments. For example, the social constructionist approach often emphasizes the remaining abilities of people with dementia. Sabat (2001) called on people to recognize "the cognitive and social abilities which remain intact despite a variety of losses," and claimed that "the remaining abilities of those afflicted can reveal intact aspects of selfhood, their humanity, and the continuum of human experience" (p. x). However, this emphasis on remaining abilities may exclude people with dementia in the advanced stages, particularly those who are not communicating verbally or have aphasia.[11] While the work of Kontos (2006) and Hyden et al. (2014) represents an important shift by focusing on emotional and embodied expressions, the majority of research exploring the lived experience of dementia focuses on verbal methods of data collection, such as interviews and focus groups. Consequently, much of the research on the lived experience of dementia focuses on people who would be labeled "high functioning." However, people with dementia's increased likelihood of being institutionalized represents the ways that old age and disability intersect. Thus, research is needed that includes people with dementia who are institutionalized and labeled as "low-functioning." Further, it is important to explore the ways in which disability and old age are constructed in nursing homes, and how these constructions affect the lived experiences of people with dementia.

Within institutional contexts, there is a significant amount of research focusing on practical aspects of providing care, such as the attitudes and actions of staff (Zimmerman et

[11] Aphasia is "an impairment of language, affecting the production or comprehension of speech and the ability to read or write…Aphasia can be so severe as to make communication…almost impossible, or it can be very mild. It may affect mainly a single aspect of language use, such as the ability to retrieve the names of objects, or the ability to put words together into sentences, or the ability to read. More commonly, however, multiple aspects of communication are impaired, while some channels remain accessible for a limited exchange of information" (National Aphasia Association, 2014, para 1-2).

al., 2005b), quality of life (Beerens et al., 2013; Zimmerman et al., 2005a), symptoms and behaviors (Dupuis et al., 2012), environmental conditions (Jao et al., 2015), and the needs of people with dementia in long-term care (Cadieux et al., 2013). A great deal of this scholarship seeks to evaluate and improve care, which is an important goal. However, this research often does not consider the lived experiences of care workers and the people with dementia for whom they care in a sociocultural context. Thus, there is a significant need to explore how care is understood and experienced within cultural, social, and political frameworks, and how care relationships are formed through interactive moments between people with dementia and their caregivers, whom occupy different social locations.

III. METHODOLOGY AND METHODS

This project initially began the first time I stepped into the dementia unit of a nursing home when I was 16 years old, nearly 20 years ago. Since then, I have spent countless hours in dementia units in Ohio and Illinois, developing close relationships with the old people with dementia and the care workers. As demonstrated by the dearth of research on the care relationships between institutionalized old people with dementia and direct care workers, these multiply marginalized groups, who are brought together in the dementia unit, are invisible to much of society. Ultimately, this project aims to change that by telling the stories of the old women with dementia and the immigrant women of color employed to care for them in the dementia unit of Cedarwood Care Center. This chapter delineates the methodology and methods of my research. First, I provide an overview of the purpose of this study, the guiding research questions, and the theoretical approach in which this study is grounded. Next, I discuss ethnographic methodology, with a particular focus on why ethnography was well-suited for this specific study and how my positionality influenced my research. Then, I detail my research site, recruitment and sampling, and data collection. I also explain my process for analyzing my data, how I maintained quality and rigor, and the limitations of this study.

A. **Purpose of Study**

The purpose of this study was to explore the lived experiences of and care relationships between old women with dementia and the immigrant women of color who care for them, and analyze how institutional, social, cultural, political, and structural factors intersect to influence interactive moments, relationships, and acts of care in an institutional context. This research is important because although care is a gendered, racialized, classed, aged, and disabled experiences, there is a dearth of research examining dementia

care from an intersectional perspective (Crenshaw, 1991). Thus, my research fills an important gap by centering old women with dementia who are experiencing institutionalization and the women employed to care for them and analyzing how social location influences their lived experiences and care relationships.

B. **Research Questions**

My central research question was, “How do institutional, social, cultural, political, and structural factors influence the care relationships between old women with dementia and immigrant women of color employed to care for them within dementia units of nursing homes?” To address this research question, my work endeavored to answer the following specific questions:

(1) What are the lived experiences of old women with dementia who live in long-term care settings, and the women employed to care for them? How do social identities influence these lived experiences?

(2) How do age, disability, gender, race, class, immigrant status, and other social locations intersect to influence care relationships between old women with dementia and their women caregivers in an institutional context?

(3) How do the structures of the dementia unit, nursing home, and broader U.S. society influence care relationships between old women with dementia and their women caregivers in an institutional context?

To answer these questions, I employed an ethnographic methodology grounded in a critical theoretical framework and collected data using participant observation, interviewing, and archival research.

C. **Theoretical Approach**

This study is grounded in a critical theoretical framework, which aims to examine and critique systems of power, privilege, and oppression with the ultimate goal of emancipation (Creswell & Poth, 2018). According to Lincoln et al. (2011), researchers using a critical paradigm believe "human nature operates in a world that is based on a struggle for power. This leads to interactions of privilege and oppression that can be based on race or ethnicity, socioeconomic class, gender, mental or physical abilities, or sexual preference" (p. 102). Given this study's emphasis on studying how disability, age, gender, and other social locations intersect to influence lived experience and institutional care, this research draws specifically on intersectionality as an analytic.

Intersectionality is a Black feminist framework for examining how social identities and forms of oppression (e.g., racism and sexism) intersect (Anzaldúa, 1987; Combahee River Collective, 1977; Crenshaw, 1991; Lorde, 1984). As I wrote in my previous work, drawing on the work of Bowleg (2008), "Intersectionality challenges the idea that an individual's lived experience is grounded in a single social identity and that axes of power and oppression can be examined and understood singularly" (Gibbons, 2016, p. 74). As an analytic, intersectionality seeks to uncover and challenge interlocking systems of oppression. Collins and Bilge (2016) explained:

> Intersectionality as an analytic tool examines how power relations are intertwined and mutually constructing. Race, class, gender, sexuality, dis/ability, ethnicity, nation, religion, and age are categories of analysis, terms that reference important social divisions. But they are also categories that gain meaning from power relations of racism, sexism, heterosexism, and class exploitation. (p. 7)

Intersectional analyses often center racism, sexism, and classism but less frequently engage with ableism and ageism (Erevelles & Minear, 2010). To understand the complex

interweaving of oppression in the dementia unit of a nursing home, it is essential to consider ableism and ageism in addition to racism, sexism, classism, and xenophobia. Lewis (2020) defined ableism as:

> a system that places value on people's bodies and minds based on societally constructed ideas of normalcy, intelligence, excellence, and productivity. These constructed ideas are deeply rooted in anti-Blackness, eugenics, colonialism, and capitalism. This form of systemic oppression leads to people and society determining who is valuable and worthy based on a person's appearance and/or their ability to satisfactorily [re]produce, excel, and 'behave.' (para 4)

Ableism, as understood by Lewis, permeates spaces like dementia units, and affects both the old women with dementia living there and the immigrant women of color employed to care for them. This understanding of ableism as intertwined with sexism and racism gestures toward what Jina B. Kim (2017) has termed a "crip of color critique," which is "a mode of analysis that urges us to hold racism, illness, and disability together, to see them as antagonists in a shared struggle, and to generate a poetics of survival from that nexus" (para 2). Kim further elaborates that a crip of color critique centers precarious populations and understands the State not as a site of protection but as a site of control and violence. Institutionalization is one way that the State and capitalism intersect to simultaneously provide old disabled people and care workers with a means of survival while also subjecting them to debilitation, isolation, exploitation, and violence.

Furthermore, ableism and ageism are intricately connected, particularly in the context of a nursing home. Cohen (1988) explained:

> American ageism is focused upon the elderly with disabilities…the elderly themselves have concluded that when disability arrives, hope about continued growth, self-realization, and full participation in family and society must be

> abandoned so that all energy can be directed toward the ultimate defeat which is not death but institutionalization. (p. 25)

Thus, intersectionality offers a way for scholars to consider how disability and age intertwine with race, gender, class and other social identities in later life and throughout the life course. As I noted in previous work, “Using an intersectional approach is not just additive but considers how institutional and structural oppression related to age and disability, as well as race, sex, gender, class, and sexual orientation, come together” (Gibbons, 2016, p. 74). These forms of oppression interlock and serve to mediate the lived experience of old/disabled women and direct care workers in a sociocultural context of ageism, ableism, and sexism.

D. Ethnographic Methodology

Dementia units of nursing homes are highly segregated spaces, out of view from the community and society, which creates numerous challenges for understanding the life worlds of old women with dementia and their care workers. In order to explore the lived experiences of old women with dementia and the women who care for them in an institutional context, I conducted an ethnographic study of a dementia unit in a nursing home in the Chicagoland area for nine months.

1. Overview of Ethnography

Ethnography is a form of qualitative research in which researchers immerse themselves in the day-to-day lives of participants to study their experiences within their cultural and social framework. As O’Reilly (2012) noted, “Ethnographic research...suggests we learn about people's lives...from their own perspective and from within the context of their own lived experience” (p. 84). Ethnography is a complex methodology that serves as a “way of seeing” through the lens of culture (Wolcott, 1999). While other qualitative

methodologies may draw on similar methods (e.g., interviewing), ethnography is unique because the researcher becomes deeply involved in the lives of participants. Due to the immersive and long-term nature of ethnography, it is described as iterative-inductive research, meaning that the design of the study is flexible and evolves throughout the research process, and data collection and analysis occur at each stage (Livingston, 2005; O'Reilly, 2012).

2. Ethnography in Diverse Sites of Confinement

Ethnography has been used to study diverse forms of confinement, ranging from psychiatric institutions and asylums (Biehl, 2013; Goffman, 1961) to prisons (Hanley, 2010; Owen, 1998; Rhodes, 2004) to residential care and nursing homes (Leibing & Cohen, 2006; Jaffe & Wellin, 2008; McLean, 2006; Stafford, 2003; The, 2008). Confinement is a complex experience, and to understand the culture of confinement is an arduous task, particularly since it extends beyond the walls of institutions into social foundations including the economy, public policy, and the media (Brown, 2009). Furthermore, the subjects of studies of confinement are typically people who are multiply marginalized across axes of race, gender, class, age, and disability, which further complicates the process of understanding their experiences with confinement, particularly since researchers are typically operating from different positionalities and are rarely, if ever, confined with participants (Owen, 1998). However, despite these challenges, ethnography is one of the most useful and well-suited methodologies for studying confinement.

3. Advantages to Ethnography in Studying Confinement

One of the key strengths of ethnography is that researchers immerse themselves in the life worlds of their participants to the greatest extent possible, for significant periods of time. A significant outcome of this level of involvement is the

researcher develops relationships with the participants, often in ways that other qualitative methodologies would not allow. Trust and rapport are important to establish in all qualitative research (Patton, 2002), but can be much more difficult to establish in spaces of confinement, particularly if a researcher is only entering the institution for short periods of time to administer surveys or conduct interviews. Ethnographers of various forms of confinement have noted that in the initial period the study, inmates/residents and staff did not trust their presence (McLean, 2006; Owen, 1998). Many expressed concerns that the researcher was an “agent” or “spy” of some group in power – for example, inmates of prisons and residents of nursing homes were fearful the researcher was reporting back to the staff, and staff in these spaces were concerned the researcher was working for the administration. Thus, due to the entanglements of privilege, power, and oppression in institutions (Goffman, 1961), researchers must establish themselves as committed and trustful over time, and build relationships with participants, which ethnography supports due to its immersive and long-term nature.

Another advantage of the deeply engaged aspect of ethnography is it allows for researchers to observe and participate in everyday activities. Regardless of their stated purpose, institutions share highly routinized and heavily controlled environments, which heavily influence the experiences and lives of inmates/residents. In a study of nursing home culture, McLean (2006) explained:

> To gain a closer understanding about life as a nursing home resident, ethnographers try to partake in the lifeworld of the residents, to experience the care routines to which they are subjected, and, insofar as they can, to share in their various joys, sorrows, and tribulations. (p. 65)

Similarly, in her study of residential facilities for incarcerated mothers, Haney (2010) discussed the importance of understanding day-to-day occurrences and routine

experiences, noting that how an institution structures routines and the daily existence of inmates and staff reveals the “patterns of power and regulation that shape, guide, and manage social conduct” in the context of confinement (p. 7). Certainly, routines and everyday experiences can be studied in other ways, but methodologies guided primarily by interviews often are inadequate to capture what has become mundane and unremarkable to people in institutions. As O’Reilly (2012) claimed, ethnography seeks to make the strange familiar and the familiar strange. Occurrences that may seem ordinary to inmates/residents and staff and thus not worth mentioning in an interview are better understood by observing and participating in the day-to-day life of participants.

Relatedly, involvement in the daily life of participants over a period of time also allows for a deeper understanding of the context to emerge that surveys or interview with participants may not singularly produce. While formal interviews often take a person out of their context and ask them to reflect on and relate their experiences to the researcher, participant observation allows for researchers to witness firsthand what occurs in spaces of confinement, and how people respond to or make meaning out of these occurrences. It also allows for the emergence of issues that people may feel uncomfortable bringing up in formal interviews for a variety of reasons, such as feelings of embarrassment, shame, guilt, regret, distrust, and fear. The (2008) conducted an ethnography of end-of-life issues for people with dementia in two nursing homes in the Netherlands, and observed:

> Some of the most important information, especially relating to sensitive or taboo topics, tends to surface in informal conversations in corridors or coffee rooms rather than formal interview settings. If I had used different methods I would probably have learned little about the rough treatment of residents, the cultural gap between different ethnic groups or carer’s double jobs. Participant observation is the only way to study certain topics. (p. 11)

In the context of confinement, there are numerous sensitive topics that may arise, particularly around the key penal correlates of exclusion, isolation, blame, and infliction of pain (Brown, 2009). These experiences may not be readily talked about in a formal interview but may surface over time through participant observation and the building of relationships based in rapport, respect, empathy, and trust.

Another reason ethnography is an ideal methodology for this project is that it allows diverse forms of data collection. Often, interviews, archival research, and other methods are utilized to supplement participant observation, allowing researchers to study complicated phenomenon. For example, a key aspect of institutionalization is the interactions, exchanges, and relationships between people who are confined and the staff employed at the institution. It is easy to view relations between inmates/residents and staff through the lens of a hierarchy, with the staff enacting power over the inmates/residents, but Brown (2009) cautions that is too simplistic, and that staff and residents actually share a sense of isolation and difference:

> What prisoners, prison workers, and those who care about them share is an extreme difference and isolation from society—a sense that they are ultimately disposable and most socially valuable when invisibly fulfilling the warehousing mandate of a society that has come to view incapacitation as the first and most logical political and social choice in dealing with a vast array of issues, some crime-related and many not. (pp. 3-4)

Often, although staff and inmates/residents are certainly positioned differently, they both experience marginalization in the context of confinement. For example, the majority of caregivers of old people with dementia are women marginalized by race, class, and immigration status, who are paid low wages with minimum or no benefits for difficult and disabling care work (Allen & Cherry, 2006; The, 2008). Thus, the interactions and

relationships between inmates/residents and staff in the context of confinement are multifaceted, and ethnography is an important way to systematically study this aspect of institutionalization. As ethnography permits the collection of diverse forms of data, it is well-suited to engage with the complexity of issues in institutions.

Lastly, spaces of confinement produce unique cultures and subcultures, which are situated in a broader societal context in which confinement is viewed as a solution to social problems, particularly in an era of neoliberal capitalism and mass incarceration. Due to ethnography's emphasis on understanding culture, it is an appropriate methodology for exploring the culture of confinement both within and beyond institutional spaces. Institutions produce distinctive cultures in part because they hold multiple and contradictory meanings and force inmates/residents, staff, and administration into a singular bureaucratic, highly regulated, and enclosed space that is segregated from society to varying degrees (Goffman, 1961).

For example, as McLean (2007) noted about nursing homes, "The nursing home is an extraordinarily rich cultural setting in which to conduct research because of the endless conflicting expectations, demands, and agendas of its various actors, drawn together for different reasons and co-existing in an artificially created environment" (pp. 63-64). Nursing homes, prisons, and other spaces of confinement often co-exist as "homes," institutions, workplaces, regulated industries, and businesses or non-profit organizations, which produces a multi-faceted and intricate culture. Furthermore, how the different people involved in confinement (e.g., residents, staff, administration, family members and loved ones) experience that culture differs. Additionally, the broader cultural context in which institutions arise and thrive also influences the culture of spaces of confinement. Owen (1998) described the interplay of institutional culture and societal culture in her ethnography, stating:

> The world of the women's prison is shaped by pre-prison experiences, the role of women in contemporary society, and the ways women rely on personalized relationships to survive their prison terms. Women's prison culture, then, is decidedly personal, a network of meanings and relationships that create and reproduce the ways women do their time. This culture is mediated by structural forces and personal choice both within the prison and outside each woman's immediate control. (p. 8)

Hence, the culture of confinement is shaped both by the individuals living and working within institutions as well as the social forces such as politics, the economy, and ideology. Ethnography is uniquely positioned to explore these complexities.

4. **Feminist Quasi-Ethnography**

This study utilizes two forms of ethnography: feminist ethnography and quasi-ethnography. Feminist ethnography strives to examine people's lived experiences through a gendered lens, locate their realities in social and cultural contexts, and consider how gender, race, age, disability, class, and sexual orientation intersect (Owen, 1998; Reinharz, 1992). However, feminist ethnography has been criticized for obscuring power differentials between marginalized participants and more privileged researchers and presenting a universal "women's experience" that disregards axes of difference, such as race, class, and sexuality (Abu-Lughod, 1990). To address these issues, Schrock (2013) identified three methodological imperatives of feminist ethnography: (a) "producing knowledge about women's lives in specific cultural contexts"; (b) "recognizing the potential detriments and benefits of representation, exploring women's experiences of oppression along with the agency they exercise in their own lives"; and (c) "feeling an ethical responsibility towards the communities in which the researchers work" (p. 48). These methodological imperatives serve as a guide for navigating the challenges feminist ethnographers face.

Quasi-ethnography is often a necessary approach to conduct ethnographic research in a setting in which participants are confined or incarcerated, such as a nursing home, prison, or psychiatric institution. Often, the term “quasi” is applied to ethnography to refer to studies that use a decreased timescale or fewer visits to data collection sites (Murtagh, 2007). However, according to Owen (1998), quasi-ethnography may also be used to describe deviations from ‘true’ ethnography that occur because the researcher is unable to become immersed in the lives and world of participants. Hence, in the context of confinement, the structural barriers of the research site prevent researchers from fully entering the world of participants. Yet, as Owen (1998) noted, “The methodology - in-depth interviews, detailed observations of everyday life - and the analysis - describing culture in terms of the meanings and interpretation of the members under study - is approximately the same as that of true ethnography” (p. 21). Thus, quasi-ethnography is an important methodological tool for studying those experiencing various forms of confinement.

Given the unique context of this project, I elected to blend feminist and quasi-ethnography. Feminist quasi-ethnography was an ideal methodology for this study because it allows for the centering of two multiply marginalized groups: old women with dementia living in a special care unit in a nursing home and the women employed to care for them. Furthermore, it accounts for the structural barriers inherent in engaging in research with people experiencing confinement. Lastly, it allowed me to approach the participants and research within a feminist critical framework and engage in feminist praxis throughout my project.

E. **Positionality**

Historically, ethnography emerged out of anthropology as a method in which the researcher traveled to a faraway land to gain a deeper understanding of an unfamiliar culture (van Maanen, 2011). As part of this process, the researcher would spend significant

amounts of time building relationships with the people being studied in order to move from "outsider" to "insider" in the culture. Despite this desire to achieve "insider" status, ethnographers still advocated for objectivity and detachment, in order to more closely align ethnography with the principles of quantitative research (Madison, 2012). However, in contemporary ethnography, scholars have critiqued this viewpoint and called on researchers to consider their positionality. According to Madison (2012), "Positionality is vital because it forces us to acknowledge our own power, privilege, and biases just as we denounce the power structures that surround our subjects" (p. 14). Thus, researchers must reflexively engage with the ways in which their subjectivity and personal experience influences their work.

As a young, mixed race, white passing, cisgender[12] highly educated doctoral candidate, I have a significant amount of privilege that must be acknowledged as I engaged in my study of old women with dementia and the women who care for them. My participants experience structural oppression across axes of race, class, immigrant status, and age that I do not share. Acknowledging these differences allowed me to consider the ways in which my subjectivity influenced the ways I collected and analyzed data. Furthermore, the relationships I developed in the field were influenced by the aspects of my identity that my participants perceived, such as being a white passing, highly educated young cis woman. Unless I disclosed, my participants did not view me as a woman who is a mixed race daughter and granddaughter of Japanese immigrants, or as a woman who was raised by a single mother in poverty. Yet, my personal identity and the ways in which I am coded and read by others, which sometimes conflict and sometimes align, affected how I built and maintained relationships with participants.

[12] Cisgender is a term for people whose gender identity aligns with the sex they were assigned at birth.

My positionality also served as a powerful impetus for this research. My familial experiences with poverty, immigration, xenophobia, and racism have influenced my desire to engage in intersectional research that examines the experiences of old women with dementia and their formal caregivers. Furthermore, as a person with psychiatric disabilities and a trauma survivor, I do not remember significant portions of my childhood, which has led me to identify with people with dementia on a deep level, despite not sharing diagnoses or impairments. I do not believe that the ability to access memories or engage in linear narratives, which bring the past into the present, are a part of personhood. Thus, being labeled as “out of my mind” has prompted me to explore the lived experience of old women with dementia.

F. **Ethical Considerations**

Ethnography is a relational methodology, and thus, a key aspect of ethics is considering the effect one’s research may have on others. Historically, people with dementia have been excluded from research, particularly if they are institutionalized (Ries et al., 2017). Given that the global population is aging and the number of people experiencing dementia is growing, including people with dementia in research is becoming increasingly important. Additionally, people with dementia have adopted the Disability Rights Movement framework of "Nothing About Us Without Us." Activists with dementia critique research that only includes the perspectives of doctors and caregivers, and advocate for people with dementia to be included in research. Consequently, in recent years, scholars and activists have increasingly argued that people with dementia can and should participate in research with proper accommodations (Novek & Wilkinson, 2019; Ries et al., 2017). This study was approved by the Institutional Review Board at the University of Illinois at Chicago (see

Appendix A), and I engaged in multiple strategies to ensure that people with dementia were able to participate and the research was ethical.

G. **Site**

This research occurred in the dementia unit of Cedarwood Care Center, a skilled nursing home. According to the U.S. Department of Health and Human Services (2000), a skilled nursing home is:

> an institu which has a transfer agreement in effect with one or more participating hospitals…and which is primarily engaged in provided skilled nursing care and related services for residents who require medical or nursing care; or rehabilitation services for the rehabilitation of injured, disabled, or sick persons. (p. 2-5)

Skilled nursing differs from independent living or assisted living. Old people typically enter skilled nursing following an injury or illness that requires rehabilitation or after they have a significant decline in health that requires more intensive care. Whereas independent living typically only offers no to minimal assistance and assisted living offers minimal to moderate assistance (such as help getting dressed or managing medications), skilled nursing offers 24-hour nursing care and medical supervision. Dementia care is a specialized aspect of skilled nursing, and not all nursing homes have dedicated units for people with Alzheimer's and other dementias. Skilled nursing homes are required to have 24-hour nursing care and are also heavily staffed with Certified Nursing Assistants (CNAs), who assist residents with their Activities of Daily Living.

Although approximately 70% of nursing homes are for-profit, Cedarwood Care Center is a non-profit. For-profit nursing homes have been criticized for prioritizing profits over care, and research has indicated that disabled old people frequently receive better care at non-profit facilities (Comondore et al., 2009; Lu & Lu, 2019). Cedarwood Care Center is also religiously affiliated; it is owned and managed by a Jewish non-profit

organization but accepts people of all religions. It has been in operation for almost 40 years. Cedarwood Care Center's mission is to provide excellent medical care, improve residents' quality of life, and serve the Jewish and broader Chicagoland community. Presently, they have 240 rooms and at any given time approximately 215-240 residents. Each resident has a private room, which many of the staff refer to as "apartments." Given their Jewish affiliation, Cedarwood Care Center serves all kosher food and offers synagogue services. Cedarwood Care Center also has a residents' council, which is an opportunity for residents to voice their concerns and suggest improvements, although no residents from the dementia unit were on the council. Overall, Cedarwood Care Center is a highly-rated facility. It was recently ranked as one of the top nursing homes in Illinois and is trusted and valued in the Jewish and broader Chicagoland community.

1. **Demographics**

Cedarwood Care Center did not compile complete demographic data on a regular basis, so demographic information is incomplete and based on the limited data available. These demographics refer to the entire facility; demographics of the dementia unit are detailed below. Approximately 66.9% of residents are women, and 33.1% are men. Residents' ages ranged from roughly 55-105 years old; the average age is 83 years old. Among residents whose religion was known, the majority of Cedarwood Care Center residents are Jewish (77.3%); other represented religions include Christian (18.7%), Buddhist (1.1%), Muslim, and Hindu. At the time resident data were collected, among residents whose race and ethnicity were known,[13] 93.5% were white, 3.6% were Black, and 2.4% were Asian/Pacific Islander, although during my research I observed Cedarwood Care

[13] At the time of this research, Cedarwood Care Center was attempting to streamline their resident demographic data collection process, but existing data was incomplete and the racial and ethnic identities of some residents was unknown.

Center becoming more racially diverse. The nursing home also serves a significant number of Russian-speaking Jewish immigrants. Some of the nursing home residents are survivors or the children of survivors of the Holocaust.

An estimated 53% of residents have Alzheimer's or another form of dementia, but only about 40% of those with dementia are housed in the dementia unit. Other major health conditions and disabilities residents have included hyperlipidemia (71%), ischemic heart disease (69%), congestive heart failure (62%), arthritis (62%), depression (50%), diabetes (40%), atrial fibrillation (33%), chronic obstructive pulmonary disease (27%), cancer (23%), asthma (20%), stroke (20%), and schizophrenia (15%). The average length of stay at Cedarwood Care Center is 28.2 days, but this average is brought down significantly by the rehabilitation unit, which only houses residents on a short-term basis and has regular turnover. Residents in other units, including the dementia unit, were long-term stays, and these residents lived in the nursing home for years and typically stayed in the nursing home until death.

2. **Location**

Cedarwood Care Center is located in the Chicagoland area. It is adjacent to a hospital and a cemetery, and also close to numerous restaurants and shopping centers. Despite the proximity to a hospital and numerous businesses, Cedarwood Care Center is relatively quiet. It offers a large private parking lot for doctors, nurses, certified nursing assistants, and visitors. There are two fenced in outdoor areas, accessible from the ground floor. The outdoor areas have trees, flower beds, sculptures, and areas to sit.

3. **Structure**

Cedarwood Care Center has seven floors. All the floors are primarily accessible by elevators. There are three elevators, one of which is also used by cleaning,

laundry, and kitchen staff. The first floor contains the main lobby, a great hall with a library, small in-home theater, and computer stations, a social hall and synagogue for community and religious events, and a gift shop. The second floor houses the administrative offices, conference rooms, break rooms with lockers for the direct care staff, a hair salon, an art therapy room, and physical therapy rooms. The remaining five floors accommodate residents. The floors are segregated according to residents' dis/abilities and care needs. The third floor is "total care"—residents who need assistance with all of their Activities of Daily Living (ADLs), such as eating, dressing, toileting, and transferring between beds and wheelchairs. Quite a few of the residents on the third floor are non-verbal and essentially all of the them require assistance for mobility. The fourth floor is short-term rehabilitation, which assists residents as they recover from an injury, accident, or illness. These residents receive regular physical, occupational, and speech therapy, as the goal of the rehabilitation unit is to help residents recover and return to their homes and "everyday lives." Whereas most residents in other units of Cedarwood Care Center are funded through private pay, private insurance, and Medicaid, the majority of residents in the rehabilitation unit are funded through Medicare, which is a major source of income for Cedarwood Care Center and other nursing homes (Rodriguez, 2014). The fifth floor is the Alzheimer's Special Care Unit, which houses residents with Alzheimer's disease and other forms of dementia, and I discuss this unit in more detail below. The sixth and seventh floors are "partial care"—residents who only need some assistance with their ADLs. The seventh floor houses the most independent residents and the sixth floor houses the second most independent residents. These residents receive the least oversight and supervision, and many are free to move about their floor and the facility as they please.

Although Cedarwood Care Center is not considered a Continuing Care Retirement Community, residents were moved between floors if it was determined their needs and

dis/abilities were changing. For example, during my research, I observed three residents with advanced dementia move to the total care floor. I also observed quite a few residents being transferred from other floors. Several residents who came to Cedarwood Care Center for short-term rehabilitation were ultimately transferred to the dementia unit after their assessment demonstrated they had Alzheimer's or another form of dementia and their care team determined they would benefit from being in the dementia unit. The verticality of the floors in conjunction with the segregation of the residents according to their dis/abilities and care needs symbolized decline—with the exception of the rehabilitation unit, the closer one was to the door, the less "independent" one was.

My research occurred in the dementia unit on the fifth floor. The unit is divided into four wings, which are labeled A-wing, B-wing, C-wing, and D-wing. Each wing contains 12 rooms and houses 12 residents. Each wing also has a common area. The maximum occupancy of the dementia unit is 48 residents, and it was, for the most part, consistently full. As the only "secure" (i.e., locked) floor, the dementia unit was perhaps the most segregated unit in Cedarwood Care Center. Residents wore a band around their wrists, ankles, or on their mobility devices (i.e., wheelchairs, walkers) that sent a signal to stop the elevators and held the elevator doors open. The elevators would not move again until a code was entered by a care worker. Regardless of whether they were labeled as "high-functioning" or "low-functioning," residents could only leave the unit if supervised by the Activity Director, a Physical, Occupational, or Speech Therapist, the Art Therapist, or a family member. Even CNAs and nurses were not permitted to leave the unit with residents. With the exception of a few residents who were labeled "high-functioning" and thus were invited by the Activity Director to attend services in the synagogue or be a part of events like the Annual Talent Show, the majority of the residents never left the unit unless taken out by a family member. A significant number did not leave the unit at all for the duration of my

fieldwork. Given this, I conducted virtually all of my research in the dementia unit. However, I was always acutely aware that I, unlike the residents, had the power to leave, and that at the end of each day, I would. After I had been conducting research in the dementia unit for a month or so, I was even trusted with the elevator codes. Residents from other floors never entered the unit, with one exception—a man in the rehabilitation unit visited his wife in the dementia unit during the short time they were there. Other than this, I never observed visits from other residents at Cedarwood Care Center. The most common visitors were family, but typically the adult children of residents. I rarely saw children in the dementia unit. Overall, the residents in the dementia unit were highly segregated—from residents in other units, from their families, and from their communities.

Cedarwood Care Center made efforts to structure and decorate the dementia unit so that it felt "homelike." There were couches and armchairs in the entrance and common area of every wing, art on the walls, bookcases filled with books, and a fish aquarium in the entrance to the unit. Each wing was painted a different color. Residents were encouraged to display photos and art in their rooms and were permitted to bring small pieces of furniture. However, there was no denying that the dementia unit was more institution than home. Each wing looked relatively the same, the colors were all muted, there was no carpet (as it was deemed a tripped hazard for people with dementia), and nursing carts were nearly always in full view. Although it would sporadically smell of urine and feces, the dementia unit generally smelled clean but in a sterile way. The CNAs wore maroon scrubs, the nurses wore sky blue, and physical, occupational, and speech therapists wore navy. Their scrubs immediately differentiated their roles. Cleaning, laundry, dining, and maintenance staff also wore uniforms. When CNAs wore more colorful clothes or accessories (for example, a colorful top with the maroon scrub pants), they were reminded they needed to dress according to the rules. The care workers also wore name badges which were attached to

secondary badges that displayed the various institutional emergency codes (e.g., code red for fire or code blue for medical emergency) and “the nine types of elder abuse” (e.g., physical, sexual, mental, verbal, involuntary seclusion, exploitation, misappropriation, mistreatment, and neglect). Ultimately, many of these features caused the dementia unit to feel more like a hospital than a home, although it was certainly both for the residents.

H. Recruitment and Sampling

Recruitment for this study occurred in two phases. In the first phase, I recruited old women with dementia and care workers to participate as I engaged in observation, which over time evolved into participant observation, and conducted informal interviews. In the second phase, after immersing in participant observation and administering informal interviews for approximately six months, I recruited participants for formal interviews.

1. Recruitment for Participant Observation and Informal Interviews

Prior to data collection, I received permission from administrators at Cedarwood Care Center to engage in research in communal, non-private areas of their dementia unit, such as the lobby at the entrance of the unit, the living space in each wing, and the dining room. I distributed a study information sheet to the nursing home administrators and to all part-time and full-time staff in the dementia unit. No staff requested to be excluded from the study. Every resident in the dementia unit had a legally authorized representative (LAR) who acted as their proxy for informed consent. The nursing home administrators communicated to the residents’ LARs that I would be conducting research in the unit and distributed my study information sheet to them. No LARs requested that any person with dementia be excluded from the study.

2. **Recruitment for Formal Interviews**

To recruit old women with dementia for formal interviews, I first met with the Unit Manager/Head Nurse, Brenda. During this meeting, I provided Brenda with a list of four residents who I felt, based on my observations, would be able to participate in a formal interview. Brenda suggested an additional two residents and I agreed with her assessment. Brenda then contacted the LARs for each resident. All but one LAR agreed that the resident could participate in the interview. The LARs then signed the consent form the next time they were in the dementia unit, or, if the LAR lived out of state, the LARs gave Brenda consent to sign on their behalf. After the LAR had provided written consent, I approached the old women with dementia and, using accessible language, explained the purpose of my study and asked them if they would be willing to assent to participate. All five old women with dementia agreed.

Unfortunately, recruiting staff for the interviews proved to be more difficult, which I had not expected while designing this study. Although the majority of the CNAs expressed that they wanted to help, many indicated they could not do an interview. A significant number of the CNAs worked second jobs, were raising children, taking care of parents, grandparents, and neighbors, and thus did not have time to participate in an interview. Several of the CNAs for whom English was their second language explained to me they did not think they would be able to express themselves in the way that they wanted in an interview in English. One CNA told me that she did not want to participate in an interview due to the stress of the job and her need to have boundaries. She asserted, “When I am not here, I don’t want to think about this place.” Ultimately, I was able to recruit four care workers for my research – three CNAs and one nurse. I had the distinct sense that these four participants agreed to do an interview to help me, as though they felt invested in ensuring I met my goals and received my Ph.D. I attribute this to the relationships and

rapport I was able to build with the care staff over time and am grateful for their willingness to speak with me.

3. **Sampling**

I used criterion sampling for this study. According to Patton (1990), "The logic of criterion sampling is to review and study all cases that meet some predetermined criterion of importance" (p. 176). Given this, criterion sampling is useful in identifying information-rich cases and establishing quality assurance. To be included in this study, participants who were care workers were required to:

1. Self-identify as women or femmes;[14] and
2. Work in the Alzheimer's Special Care Unit of Cedarwood Care Center.

Participants who were old women with dementia were required to:

1. Self-identify as women or femmes; and
2. Live in the Alzheimer's Special Care Unit of Cedarwood Care Center.[15]

These criteria ensured this study centered old women with dementia and the women who provide their care in an institutional setting. This study focused specifically on old women with dementia and care workers in the dementia unit, but I included loaner CNAs, male CNAs, and old men with dementia in my field notes when they were interacting with participants or when participants referenced them in informal or formal interviews. However,

[14] Femme is a queer gender expression in which one embraces a feminine presentation but does so intentionally, for themselves and other women, not due to societal pressures or the male gaze. This term originated in the lesbian community as an identity claimed by lesbians and bisexual women with feminine presentations but today is also often used to describe trans and non-binary people with feminine presentations.

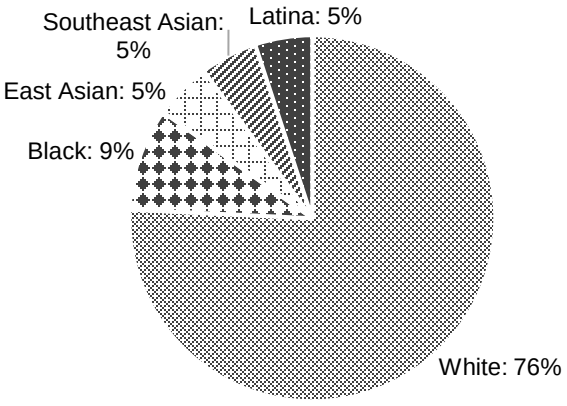
[15] Old age in American society is a social, political, and economic construction and is typically defined chronologically as 65 years old or older. I elected not to define participants as old based on their chronological age, but rather based on their institutionalization in the dementia unit in a nursing home, which is a societal marker of old age. Although young and middle-aged disabled people have been institutionalized in nursing homes, nursing homes are culturally understood as a place "for" old people and thus nursing home residents are ascribed the label of "old age." For a discussion of how old age is defined and constructed, see Settersten and Mayer, 1997.

I did not classify them as participants and they are not included in the description of the participants below.

4. **Participants**

This study included 41 participants who were old women with dementia. Thirty-one of the old women with dementia were white (76%), four were Black (9%), two were East Asian (5%) two were Southeast Asian (5%), and two were Latina (5%) (shown in Figure 1: Racial/Ethnic Demographics of Old Women with Dementia).

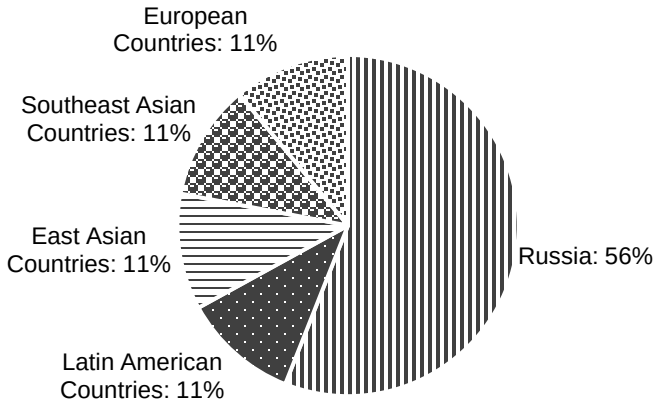
Figure 1: Racial/Ethnic Demographics of Old Women with Dementia (n=41)



Approximately 30 (73%) of the participants were Jewish. There were no Jewish people of color in the sample, although it is important to note that many of the Jewish old women with dementia did not understand themselves as white and identified their race and religion as

Jewish.[16] Approximately eighteen (44%) of the old women with dementia were immigrants who did not speak English as a first language or at all. Of the immigrant old women with dementia, ten (56%) were immigrants from Russia, two (11%) were immigrants from Latin American countries, two (11%) were immigrants from East Asian countries, two (11%) were immigrants from Southeast Asian countries, and two (11%) were immigrants from European countries (shown in Figure 2: Country of Origin of Old Women with Dementia).

Figure 2: Country of Origin of Immigrant Old Women with Dementia (n=18)



[16] Although a history of Jewish people in the United States is beyond the scope of this project, it is essential to acknowledge that North American Jews have experienced various racial classifications, at times being categorized as "other" and, after World War II, being generally accepted as white. However, racism, anti-Semitism, and xenophobia have intersected throughout much of American history particularly during periods of time when the old women with dementia in this study were children or young adults. In her book *How Jews Became White Folks: And What That Says About Race in America*, Brodkin (1998) traced how Jews have experienced a sort of "racial middleness," as they have been othered with regard to whiteness yet ultimately accepted as white in the context of anti-blackness. In 2016, after the election of President Donald J. Trump, Brodkin wrote an op-ed in Forward Magazine acknowledging that the Trump regime may "unwhiten" and mark Jews as "other" once again—a prediction that has come true as anti-Semitic sentiments and acts are on the rise.

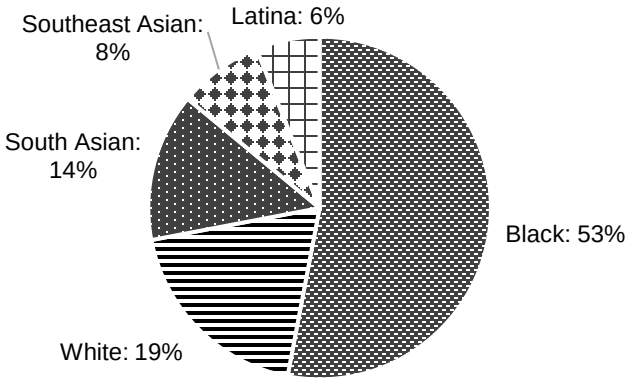
The participants' ages ranged from approximately 70 years old to over 100 years old. To my knowledge, all the old women with dementia identified as cisgender. I recruited five participants with dementia to participate in formal interviews. Three participants were white and Jewish (60%), one was Black (20%), and one was Southeast Asian (20%).

There were 36 participants who were care workers. I defined care worker broadly as any employee at Cedarwood Care Center who worked in the dementia unit part-time or full-time and played a role in contributing to the residents' physical, emotional, social, or spiritual well-being. There were twenty-one Certified Nursing Assistants (CNAs) (58%), seven Nurses (19%), and one Unit Manager/Head Nurse, Care Coordinator, Activity Director, Art Therapist, Cleaning Staff, Dining Services Staff, Laundry Staff, and Rabbi (2.875% each, 23% total).

As is typical in nursing homes across the United States, the majority of care workers in this sample were women of color and many were also immigrants from West African, Caribbean, South Asian, Southeast Asian, and Latin American countries. Nineteen of the care workers were Black (53%); of the Black care workers, eleven were born in the U.S. (58%), six were immigrants from West African countries[17] (31.5%), and two were immigrants from Caribbean countries (10.5%). Seven care workers were white (19%); of the white care workers, five were born in the U.S. (71.5%), and two were immigrants from Eastern European countries (28.5%). Five care workers were South Asian (14%), all of whom were immigrants. Three care workers were Southeast Asian (8%), all of whom were also immigrants. Two care workers were Latina (6%), both of whom were also immigrants (shown in Figure 3: Racial/Ethnic Demographics of Care Workers).

[17] To preserve confidentiality, I do not specify the nations from which care staff emigrated.

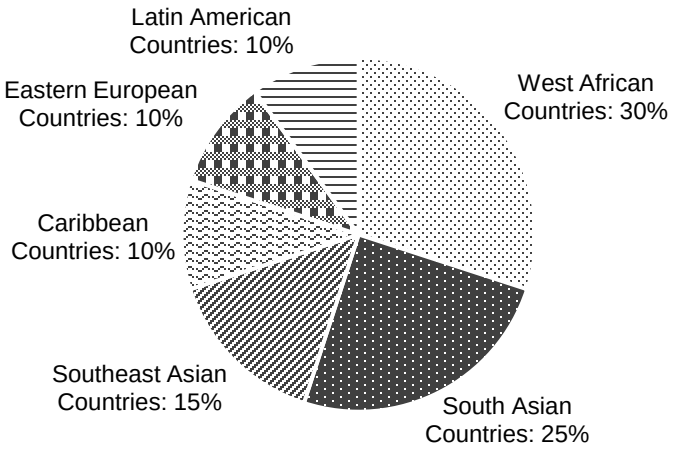
Figure 3: Racial/Ethnic Demographics of Care Workers (n=36)



Across all care workers, twenty were immigrants (55.5%) and sixteen were born in the U.S. (44.5%). Of those who were immigrants, six were from West African countries (30%), five were from South Asian countries (25%), three were from Southeast Asian countries (15%), two were from Latin American countries (10%), two were from Caribbean countries (10%), and two were from Eastern European countries (10%) (shown in Figure 4: Country of Origin of Immigrant Care Workers).

It is important to note that race and immigration status influenced the positions care workers held. As is typical in U.S. nursing homes, the majority of CNAs were women of color and immigrants. Of the CNAs, thirteen were Black (61.9%), nine of whom were born in the U.S. (70%) and four of whom were immigrants (30%); five were South Asian immigrants (23.8%), two were white Eastern European immigrants (9.5%), and one was a Latina immigrant (4.8%). White women born in the U.S. were more likely to be in positions of authority such as Nurse, Head Nurse/Unit Manager.

Figure 4: Country of Origin of Immigrant Care Workers (n=20)



The care workers ages ranged from approximately 25 years old to 60 years old, with the majority of care workers being in their 30s and 40s. I recruited four care workers to participate in formal interviews. All four (100%) participants were Black; three were CNAs and were born in the U.S. and one was a nurse and an immigrant from Africa.

I. Data Collection

Ethnographers employ a set of methods which allow them to experience, inquire, and examine in order to gain an understanding of a specific culture (van Maanen, 2011; Wolcott, 1999). This ethnography drew from a set of methods common to ethnography, including participant observation, interviewing, and archival research. To describe my data collection, I first define participant observation, interviewing, and archival research and then explain how I deployed these methods.

1. Participant Observation

The central data collection method for this study was participant observation, which is sometimes also referred to as fieldwork (de Laine, 2000; O'Reilly, 2012; van

Maanen, 2011; Wolcott, 1999). The purpose of participant observation is for the researcher to become deeply involved in the everyday experiences of the people being studied. According to van Maanen (2011):

> Fieldwork asks the researcher, as far as possible, to share firsthand the environment, problems, background, language, rituals, and social relations of a more-or-less bounded and specified group of people. The belief is that by means of such sharing, a rich, concrete, complex, and hence truthful account of the social world being studied is possible. (p. 3)

Hence, ethnographers engage in fieldwork to study the words and actions of participants in the context in which they occur.

Participant observation calls on researchers to experience people's daily lives through both observation and participation over a period of time. As Wolcott (1999) stated, the method emphasizes "the human capacity for observation" and is based on the recognition that "ultimately everything we know comes to us" through observing and participating (p. 46). Although ethnographers tend to emphasize what they see and hear (Wolcott, 1999), participant observation is a multisensory experience (Hammer, 2013).

A key task in participant observation is working to balance observation with participation. O'Reilly (2012) noted:

> Participating and observing are key elements of participant observation but the term is something of an oxymoron. The roles and aims of participation and observation can vary with an ethnographer's philosophical position, relationship to the group, routes of access and roles adopted, and as a result of practical considerations. (p. 110)

Thus, participant observation is a complex process, and ethnographers often experience tension in determining how much to participate and how much to observe. Generally,

contemporary ethnography seems to favor participation over observation (de Laine, 2000), but there is recognition that there is no universal guideline applicable to all research. As Börejesson (2014) observed, “The nature of fieldwork is not presented with consensus: Every experience is unique, as each fieldworker brings a history and background into the field” (p. 408). Thus, the specific role of the researcher and how they balance participation and observation is dependent upon the settings, the researcher, and other factors. Furthermore, it is also important to acknowledge that the role of the researcher may change continuously in the field (Borjesson, 2014).

Participant observation occurred almost entirely in the dementia unit. I observed the daily routines of the residents, such as waking, receiving medications, sitting in communal areas, visiting with family members, friends or other guests, and dining. I also participated in activities and programs with the residents, assuming a volunteer or assistant role if needed. If invited, I spent time with residents in their individual rooms. I also observed nursing home staff as they engage in acts of care, when it was appropriate and permission was granted. In order to document field notes, I wrote in a small inconspicuous notebook or recorded voice memos. I engaged in participant observation three to five times per week for nine months and spent between two and nine hours in the unit each day. I aligned my participant observation with first and second shifts of the care staff, in order to observe how the unit changed depending on the shift and the time of the day. Unfortunately, I was not permitted to observe during the third shift,[18] but I spoke to several CNAs who had worked third shift at various points. I also commonly observed the transitions between first and second shift, and third and first shift.

[18] An administrator within the dementia unit requested that I not observe third shift. Although I am unaware of the exact reasons, it was implied that the third shift was chronically understaffed, and it was a struggle to ensure the third shift CNAs fulfilled all their duties.

2. **Inquiring: Interviewing**

Along with participant observation, interviewing is another key method of data collection in ethnography (Madison, 2012; Wolcott, 1999). Rubin and Rubin (1995) characterized interviewing as an essential aspect of participant observation. However, Wolcott (1999) differentiated between the methods, noting:

> "Interviewing" may at first seem such a natural adjunct of participant observation that one can fail to recognize the extraordinary difference that sets it apart as a way of knowing. I emphasize the major distinction between experiencing…and inquiring…to underscore the critical difference between being present as a passive observer of what is going on and taking an active role in asking what is going on. (pp. 46-47)

Hence, interviewing is an additional form of gathering information about what the researcher experiences as a part of participation observation.

Interviews may be spontaneous or planned, brief or lengthy, and can take various forms, including casual conversations, semi-structured or structured interviews, surveys or questionnaires, and life histories (Madison, 2012; Wolcott, 1999). As with participant observation, there are no comprehensive procedures for interviews to guide researchers. According to Wolcott (1999), interviewing:

> ...poses a dilemma for a field researcher: whether to intrude by interjecting one's own agenda into a research setting, or to remain silent in the hope that what one wants to know may (eventually) be revealed in some naturally occurring way. (p. 47)

Thus, researchers must be strategic, and at times make decisions in the moment, regarding how and when to pursue an interview. Various factors influence when and how an ethnographer conducts interviews, such as the purpose of the study, the context of the research, and the role the researcher is assuming.

Interviews with staff occurred in two forms. First, I engaged in brief, spontaneous conversations during participant observation. These interviews were informal, conversational, and unstructured, and were used to gain additional understanding about what I was observing. They were not audio recorded, but I did take notes by writing in a small notebook or recording an audio memo after the interview had ended. Second, I conducted semi-structured, open-ended interviews with staff. According to Torres et al., (2009), semi-structured interviews "[focus] on the participants' experiences…with additional probes to ask them to explain their own understanding of those experiences. This line of questioning…allows for rich descriptions" (p. 509). The questions I asked focused on the direct care workers' experiences caring for old people with dementia, what strategies they use to cultivate relationships with residents, what organizational, structural, and policy barriers limited their relationships with their residents, and how their social identities and the social identities of the residents influenced their relationships and ability to provide care. The interviews occurred in a location of the participants' choosing. Two participants elected to meet in the local library, but the other two asked me to interview them during their breaks while at work. The interviews lasted between approximately 45 minutes and 90 minutes. They were audio recorded and transcribed for analysis.

Interviews also occurred with old women with dementia. Despite dominant societal views that dementia results in total incapacity, numerous studies have demonstrated that some people with dementia can participate in research if adjustments to standard interview protocols are made and accommodations are provided (Jaffe & Wellin, 2008; McLean, 2006). Murphy et al. (2015) suggested that researchers can maximize the inclusion of people with dementia in research through the process of gaining consent, maximizing response, telling the story, and ending on a high.

Interviews occurred after I had spent time engaging in participant observation, and have begun establishing relationships, trust, and rapport with the participants—recognizing that they may not remember who I am or the purpose of my research. To address this, consent was a multi-step process. Written consent was obtained through each individual's Legally Authorized Representative. Murphy et al. (2015) emphasized that legal proxies should be used in order to include (rather than exclude) people with advanced dementia in research. Additionally, assent was obtained from the individual with dementia at the start of the conversation or interview. I also checked in with the participants at various points to ensure they were still comfortable answering questions. If the resident was restless, agitated, having sudden mood changes, or seemingly disengaged, I recognized this as a revocation of assent and ended the interview. Each interview was structured like an informal conversation, lasted approximately 10-30 minutes, and consist of only one to five questions. The questions were repeated or reworded as often as needed. Family members and other LARs were given the option of being present for interviews, though none elected to do so. The interviews were audio recorded with permission. To end on a high, participants were thanked and informed that their perspective was important to the research project.

3. **Examining: Archival Research**

A third method commonly used in ethnography is archival research (Biehl, 2013; Livingston, 2005; Wolcott, 1999). Archival research is typically associated with a formal collection of historical documents and records. However, Wolcott (1999) cautioned against this technical definition, stating:

> That is far too limiting for a fieldworker who may be privy to personal letters, diaries, photographs, to listening to recording of speech or music, to making or reviewing inventories of household items—all sorts of things informants may have in their

> personal possession that might be shared with the ethnographer but are not necessarily available to anyone else. (p. 47)

Therefore, archival research is broadly characterized as the examination of items produced by others. In addition to the personal items listed above, other informative documents could include newspapers, fliers, zines, policy statements, press releases, and maps. Archival research adds to other ethnographic methods to create a rich sense of culture.

Archival research occurred primarily in the form of document analysis. In order to add to my understanding of the culture of the Alzheimer's Special Care Unit and Cedarwood Care Center, I examined documents such as newsletters, signs, fliers, and event calendars. I read internal and external reports on Cedarwood Care Center. I studied Cedarwood Care Center's website, with particular attention to how they discussed the dementia unit. I also perused descriptions and reviews of the dementia unit and of Cedarwood Care Center on Google, Facebook, and senior housing websites like "A Place for Mom." During my archival research, I considered the following questions:

1. What did Cedarwood Care Center do? How did they describe their overall mission and the purpose of the dementia unit? In what ways did I observe this mission and purpose being fulfilled or not?
2. What rules and regulations were displayed for residents or their families/LARs? What rules and regulations were displayed for care workers? How did residents, families, and care workers respond to these various rules and regulations? How often did I notice these rules or regulations being violated, and what was occurring in these moments? In what situations did the rules and regulations create challenges or barriers for residents, families, or care workers?
3. What events were scheduled and advertised to residents and families? How much did the scheduled events align with the events that occurred? What events occurred

but were not scheduled and advertised? How did the care workers and old women with dementia respond to or participate in these events?

4. How was Cedarwood Care Center rated by relatives of residents and visitors? How did these ratings discuss the relationships between the residents and the care workers (or lack thereof)?
5. How was Cedarwood Care Center rated by the State? How did these ratings compare to other nursing homes in the Chicagoland area and throughout the State of Illinois?

Through this process, I was able to gain a deeper understanding of the context of long-term care and institutionalization. The archival research I conducted influenced my frame as I collected data through participant observation, conducted and reflected on informal and formal interviews, and engaged in data analysis.

J. **Data Analysis**

Ethnography is unique as a qualitative methodology as it is iterative-inductive, which means that data collection and analysis are distinct yet interwoven phases of the research process (O'Reilly, 2009). Hence, ethnographic data analysis often occurs at various points in the research process, rather than at a particular stage. O'Reilly (2009) described this ethnographic analytic process as a spiral approach, which involves "moving forward from idea to theory to design to data collection to findings, analysis, and back to theory, but where each two steps forward may involve one or two steps back" (p. 15). This study drew on this spiral approach to analysis, as I analyzed data throughout the study.

Furthermore, due to the iterative-inductive nature of ethnography, data analysis may be rife with unexpected findings and the outcome of analysis may be unanticipated. Rankin (2017) urged ethnographers to recognize that:

> the researcher's knowledge and opinions about the proposed topic and research questions(s) are unlikely to remain unperturbed during the investigation. It is impossible at the outset of the research to describe the daily tensions embedded in the…informants' work or to know what will be discovered. (p. 5)

Being aware of this aspect of ethnography is important so the researcher can remain receptive to discovery. Although I have spent an extensive amount of time in various dementia units of nursing homes, I attempted to be open to what I might find during my fieldwork.

O'Reilly (2012) emphasized that data analysis during ethnographic research should focus on storytelling. In other words, what story (or stories) can ethnographers tell to make sense of what they have found? The dementia unit was a complex social, cultural, economic, and political space but as I continued my fieldwork, I became increasingly aware that time and temporality strongly influenced how the unit functioned and the relationships between the old women with dementia and the care workers. Data were then analyzed using Jackson and Mazzei's (2012) process of thinking with theory. Jackson and Mazzei (2012) argued:

> Qualitative data interpretation and analysis does not happen via mechanistic coding, reducing data to themes, and writing up transparent narratives that do little to critique the complexities of social life; such simplistic approaches preclude dense and multi-layered treatment of data. (p. vii)

In order to counter a reductionist approach to data analysis, the process of thinking with theory encourages researchers to plug data into theory, and theory into data. As Nicolazzo (2016) explained, thinking with theory "promotes viewing the meanings, understandings, and possible implications drawn from data as multiple, varied, and diverse" (p. 543). Thus,

the process of thinking with theory can be used to analyze a common dataset using diverse, multiple theoretical perspectives.

I analyzed data of interactive moments between people with dementia, myself, and caregivers through the lenses of time and temporality, with a particular emphasis on how disability studies, gerontology, and gender and women's studies has theorized time. I examined data in the context of crip time (Kafer, 2013; Price, 2015; Samuels, 2017), queer time (Halberstam, 2005; Muñoz, 2009), time ethics (Egede-Nissen et al., 2013), chronological time vs. intrinsic time (Baars, 2009), and commodified time and labor (Glenn, 2010). I explored how interweaving these different theories allowed interpretation of the data in a way that constructed a story about how time and temporality are central to the dementia unit and the relationships that develop within the unit. By thinking with theory, multiple and diverse understandings of data become possible, and integrated theoretical approaches emerged.

K. Quality and Rigor

There are several measures of quality and rigor within qualitative research, which are often referred to as trustworthiness or goodness criteria (Lincoln & Guba, 1985). These criteria are used to evaluate the quality and worth of qualitative research. This research draws on three goodness criteria: prolonged and extensive engagement, thick description, and triangulation.

1. Prolonged and Extensive Engagement

According to Mertens (2010), prolonged and extensive engagement "asks that researchers stay long enough to get it right and observe in sufficiently diverse situations to get a full and accurate picture" (p. 256). Prolonged and extensive engagement is often considered a key feature of ethnography, although Wolcott (1987) cautions that the amount

of time spent in a research setting is context specific and does not alone indicate whether an ethnography is high or low quality. To ensure prolonged and extensive engagement, I spent nine months observing and participating at the research site, and also varied my visits so that I would be present during different shifts and times of day. In doing so, I was able to gain a more complete picture of participants' experiences and the context in which they were occurring.

2. **Thick Description**

For ethnography, a key criterion for trustworthiness is thick description (Geertz, 1973; Wolcott, 1999). Thick description refers to "extensive and careful description of the time, place, context, and culture" (Mertens, 2010, p. 259), which provides readers with a deeper understanding of the participants and research setting, and equips readers to determine what, if any, aspects of the research they can apply to other situations.

3. **Triangulation**

Triangulation involves collecting data from multiple sources or methods (e.g., interviews, focus groups, document analysis) in order to ensure the researcher has substantial data from which to draw (Mertens, 2010). By using diverse data collection methods, researchers can produce more credible conclusions. This study used data from participant observation, interviews, and document analysis, which allowed me to triangulate the data and more fully attend to the complexity of participants' experiences and the research setting.

L. Limitations

This study has several limitations. First, in ethnographies of confinement, researchers are limited in how much they can truly immerse themselves. For example, in her ethnography of a women's prison, Owen (1998) wrote:

> The very nature of the prison and the facts of my life required that at some point I leave the institution and return home. The fact of my freedom—and their confinement—prohibited my full participation in the [life] of the prison…The separation between the perspective of the free person and that of the prisoner leaves some gap in this description. (p. 22)

Although this drawback is largely due to the location of the research rather than the methodology, it is still important to acknowledge that institutions are highly controlled spaces, and impose intense restrictions on anyone who enters them, regardless of their specific role. Whether researchers are accessing psychiatric institutions, prisons, or nursing homes, they will need to go through administration and staff, who will control various aspects of the study, such as what days and times they can enter the institution, what spaces within the institution they can go and for how long, and what degrees of freedom they have to observe, participate, and speak to participants.

Second, this research occurred in a non-profit nursing home with above average ratings from consumers and the State of Illinois. Consequently, this study did not capture the experiences of people who are receiving care in for-profit nursing homes. Although efforts were made to secure a for-profit nursing home as an additional site, doing so proved to be impossible. Unfortunately, it is likely that many of the most vulnerable and marginalized elders are receiving care in these for-profit nursing homes, and future studies will be needed to ensure their experiences are represented. Relatedly, this research is occurring in the Chicagoland area, and so it also did not include people with dementia receiving care in rural areas.

M. **Conclusion**

Utilizing ethnographic methodology and methods allowed me to immerse myself in the dementia unit of Cedarwood Care Center in ways that would not have been possible had I employed other qualitative methodologies. Ultimately, this deep engagement led me to uncover the ways that time and temporality shaped the structure of the unit and served as a site of adversity and potentiality in complex ways. In the next chapter, I discuss how the dominant temporalities of clock time, institutional time, and bureaucratic time served as a nexus of power and organizing principle within the dementia unit, thereby influencing the care relationships between the old women with dementia and the care workers.

IV. DOMINANT TEMPORALITIES IN THE DEMENTIA UNIT

Within the dementia unit of Cedarwood Care Center, care was constructed and implemented through dominant temporalities. By dominant temporalities, I mean structures of time that are grounded in institutional and cultural power. As noted by Clayton and Vickers (2019), dominant temporalities have "a significant degree of determination over the manner in which time is both viewed and experienced. These may be multiple and differentially encountered, yet share a capacity to organize pasts, presents, and futures as well as everyday routines" (p. 1467). For disabled people, one of the most ubiquitous forms of dominant time is what Alison Kafer (2013) refers to as "curative time." Curative time is grounded in compulsory able-bodiedness/able-mindedness, and I would add, compulsory youthfulness, which are hegemonic ideologies that construct able-bodiedness/able-mindedness and youthfulness as natural, normal, and desirable—thus constituting disability and old age as abnormal and abject (Gibbons, 2016; Gibbons & Gibbons, 2016; Kafer, 2013; McRuer, 2006).

Furthermore, these compulsory systems that enforce able-bodiedness/able-mindedness and youthfulness are grounded in racialized and gendered norms (Kim, 2017; Schalk, 2018). Curative time represents disabled people as "out of time, or as obstacles to the arc of progress"—until they can be fixed, rehabilitated, cured, and normalized (Kafer, 2013, p. 27). Old people with dementia are also viewed as "out of time" due to their advanced age as well as their dementia—a progressive condition that constructs them as "shells of their former selves" and "the living dead" (Behuniak, 2011). Their existence outside of the possibilities of cure and normalization justifies their confinement in nursing homes—as their bodies can no longer be rehabilitated into "productive" members of society,

their bodies are rehabilitated for capitalism by becoming sources of revenue for the predominately for-profit nursing home industry (Russell, 2019).[19]

Once confined in nursing homes, old people with dementia are subject to the dominant temporalities of long-term care. The dominant temporalities at work in Cedarwood Care Center are omnipresent in nursing homes across the United States and are influenced by stakeholders within the nursing home (i.e., care staff and administration) as well as the economic, political, social, and cultural context within which nursing homes operate. This context includes the cultural pervasiveness of ableism and ageism in American society, increasing numbers of people diagnosed with dementia, long waitlists for home and community-based services waivers, direct care worker shortages, chronic understaffing, high staff turnover, and low federal and state reimbursement rates for Medicaid residents. I assert that many of these issues influence or are influenced by dominant temporalities in nursing homes.

In this chapter, I discuss the dominant temporalities at work within the dementia unit of Cedarwood Care Center: clock time, institutional time, and bureaucratic time. I argue that these temporal constructions interweave to create an "economy of time," in which time becomes constructed as a valuable commodity in dementia units of nursing homes. Time not only serves to economize and financialize care, but it also serves as the means through which the needs of people with dementia and care workers are either met or denied. Time operates in the dementia unit as good in short supply—a scarcity—that is tightly structured,

[19] Despite billions of dollars spent on research each year, there is currently no cure for Alzheimer's or other forms of dementia. Interestingly, the Alzheimer's Association (2020b) casts cure in direct contrast to nursing home care. They compare the amount spent on research funding, $2.8 billion, against the amount Medicaid and Medicare spent on dementia-related nursing home care in 2020, $206 billion. They note that Alzheimer's is "the most expensive disease in America" and argue that research toward a cure is a long-term investment that will ultimately save the government billions of dollars once they no longer have to provide care for people with dementia in nursing homes.

regulated, and controlled. Within this economy of time, time is sought after, competed for, given, and denied in ways that affect the material lives of the old women with dementia and the immigrant women of color employed to care for them.

A. Clock Time as the Foundation of Dominant Temporalities

Clock time was central to the infrastructure of the dementia unit of Cedarwood Care Center. Clock time refers to the linear progression of time as measured by clocks and calendars. According to Davies (1994), clock time is "the dominant temporal consciousness in our society" (p. 278). Clock time is used to synchronize human activity, relationships, and life courses, and structures nearly every aspect of modern North American society. As Postill (2002) noted, it "is the invisible hand of the market, state, and civil society alike" (p. 251). Clock time is understood as quantitative, and hence linear, uniform, and objective. As clock time is numerical, it can be counted and consequently is subject to a process of accounting (Oldfield, 2019). Patsavas (2017) equated accounting with neoliberal, capitalist logics of economization, financialization, and accountability. In the context of nursing homes, the accounting of clock time leads to time being ordered, calculated, measured, checked, recorded, and billed. Accordingly, clock time serves as the underpinning for institutional time and bureaucratic time, two dominant temporalities within the dementia unit of Cedarwood Care Center. In what follows, I briefly define institutional time and bureaucratic time, and then explore the ways these forms of time interacted to mediate the lived experiences of and care relationships between the old women with dementia and the care workers.

B. Institutional Time

Institutional time in nursing homes, as observed by Oldfield (2019), "structures daily life for staff and residents," thereby routinizing activities, meals, and care tasks. Institutional

time serves as the core of how nursing homes operate, as it determines and organizes how care is provided. Harnett (2010) noted, “Although routine structures daily life for most people, improvisations and impromptu changes are possible…The situation is very different for residents of nursing homes” (p. 292). Within nursing homes, routines are rigid and structured in a way to ensure everyone receives care—leaving little room for change based on individual needs or preferences. In other words, nursing home routines are based on a model of institutional care rather than individual care. At the core of institutional time and institutional care is the management of bodies, which must be “managed to fit in with the day-to-day routines and structure of the institution” (Wiersma & Dupuis, 2010, p. 284). As such, institutional time prioritizes staff convenience and efficiency, and consequently, institutional time is often inflexible and unyielding.

Goffman (1968) observed institutional time as central to the operation of what he termed “total institutions.” Nursing homes have been described as total institutions, due in part to their tightly routinized structure that aims to provide care to old people as a group rather than as individuals (Stafford, 2003). According to Goffman (1968), a total institution is defined as “a place of residence and work where a large number of like-situated individuals cut off from the wider society for an appreciable period of time together lead an enclosed *formally administered round of life*” (p. 11, emphasis added). Thus, institutional time controls virtually all aspects of life within nursing homes. Under institutional time, care staff and residents in nursing homes are subject to a rigid structure and routine to which they must conform, which is administered through bureaucratic time.

C. **Bureaucratic Time**

Like institutional time, bureaucratic time contributes to the structure of the nursing home, with an emphasis on operating the nursing home as a business and ensuring

compliance with governmental regulations for care. Bureaucracy refers to “an administrative policy-making group,” which is “characterized by specialization of functions, adherence to fixed rules, and a hierarchy of authority” (“Bureaucracy,” n.d.). Nursing homes are subject to intense bureaucracy from federal and state governments, as well as nursing home administrators. According to Titchkosky (2010), “Bureaucratic time is read and measured out in terms of the development of policy, plans, programs, and procedures that aim to address a problem in a consistent and unified fashion though regularized use of rules” (para 3). In the case of long-term care facilities, the “problem” is administering care to a significant number of old, disabled people. Many of the rules and regulations that are established to address this “problem” are connected to temporality. Bureaucratic time arranges staff shifts, measures the amount of time care staff work, establishes hourly or biweekly pay for care workers, monitors care staff’s breaks, and determines if specific outcomes were achieved (e.g., if residents were toileted at least once every two hours).

D. **Intersections of Clock Time, Institutional Time, and Bureaucratic Time**

At Cedarwood Care Center, clock time, institutional time, and bureaucratic time served as a nexus of power within which the old women with dementia and the care workers had to function. These dominant temporalities established the parameters for care in the dementia unit, largely based on the increasing economization of care, governmental regulations, the larger nursing home industry, and social and cultural beliefs related to the value of old women with dementia and the value of those who care for them. Furthermore, clock time, institutional time, and bureaucratic time created a context in which care was often defined, understood, and executed in relation to time. These temporal structures aimed to ensure basic needs were met and the nursing home would remain in operation, but simultaneously limited the possibilities for the development of care relationships

between the old women with dementia and care workers. Institutional time and bureaucratic time interwove to mediate the lived experiences of and care relationships between the old women with dementia and the care staff in multiple ways. Next, I discuss in depth how institutional time and bureaucratic time contributed to understaffing, the structure of shifts and the hourly pay of direct care workers, the daily institutional routine, the requirement of waiting for care, and the experience of watching/being watched. In exploring these phenomena, I center the voices and experiences of the care workers and the old women with dementia by including excerpts from my field notes, informal conversations, and formal interviews.

1. **(Under)staffing**

One of the primary ways bureaucratic time and institutional time intersect is staffing. The number of staff and the arrangement of staff shifts directly affected the care workers and the old women with dementia. The fewer staff there were, the less time the CNAs and nurses could spend with each resident and the more they struggled to ensure all care needs were met. Cedarwood Care Center, like many nursing homes in Illinois and across the United States, was perpetually grappling with understaffing.

Understaffing in nursing homes is a serious problem and a national issue (Geng et al., 2019; Harrington & Edelman, 2018). An investigation by Kaiser Health News and the Chicago Tribune discovered that Illinois nursing homes' staffing levels were among the lowest in the country, and that 78 percent of the state's nursing home facilities' staffing levels were below the national average (Schulte et al., 2018). Nursing home administrators statewide acknowledged understaffing is a concern, and faulted Illinois' low Medicaid reimbursement rates for nursing homes, which is approximately $151 per day, per resident. Illinois ranked 49th out of 50 in a national study of Medicaid reimbursement rates, and since

Medicaid comprises approximately 70 percent of many nursing homes' revenues, administrators argued this low rate limits their funding for staff (Schulte et al., 2018).

Daily Medicaid reimbursement rates place a temporal and economic value on caring for poor, vulnerable old people. Non-profit nursing homes, like Cedarwood Care Center, accept Medicaid residents as part of their mission to serve their community. However, they often do not accept as many Medicaid residents as for-profit nursing homes[20] because they generally spend far more on care than for-profit nursing homes—on average, $11 per day per resident[21] (McCambridge, 2016). Consequently, non-profit facilities must have enough residents who are private pay or on Medicare, which reimburse at higher rates, to remain viable as a business (Adler, 2003). The low daily Medicaid reimbursement rate in this case limits non-profit nursing homes' ability to contribute to the public good. The more Medicaid residents a non-profit nursing home accepts, the more they may be forced to cut costs in other areas, including staffing. At Cedarwood Care Center, for example, the vast majority of the residents in the dementia unit were on Medicaid, which may have contributed to staffing difficulties.

For-profit nursing homes, which comprise approximately 70% of the nursing home industry, generate revenue by: (a) recruiting residents who are private pay; (b) recruiting residents who are covered by Medicare for short-term rehabilitation and extending their stays as long as possible; and (c) filling the remainder of beds with residents covered by Medicaid, who have a lower daily reimbursement rate than private pay or Medicare but a

[20] Adler (2003) reported that the average non-profit nursing home reserves approximately one-third of their beds for residents covered by Medicaid, whereas the average for-profit nursing home reserves approximately three-fifths of their beds. Non-profit nursing homes are not able to have as many residents on Medicaid, even though serving poor old people is often part of their missions, because they spend an average of $11 a day more on care per resident than for-profit nursing homes.

[21] To put this into perspective, for a facility like Cedarwood Care Center, which could house up to 240 residents, spending just $11 more on care per day per resident would equate to $2,640 per day or $963,600 per year.

much longer average length of stay (Rodriguez, 2014; Lu & Lu, 2019). For profit facilities then cut costs in various areas, including staffing. This strategy allows for profit nursing homes to earn income despite having more residents on Medicaid. However, the low daily Medicaid reimbursement rate is subsequently blamed for a lack of investment in staff with little acknowledgement that for-profit nursing homes try to reduce cost as much as possible to produce income (Adler, 2003).

Federal guidelines for nursing home staffing were set by the Omnibus Budget Reconciliation Act, also known as the Nursing Home Reform Act of 1987, which went into effect on October 1, 1990 (OBRA 42 CFR 483.30). The law requires nursing homes to employ: (a) "a registered nurse (RN) for at least eight consecutive hours on the day shift;" (b) "licensed nurses (RNs and licensed practical nurses or licensed vocational nurses) 24 hours a day;" and (c) "'sufficient' staff to meet residents' needs" (Edelman, 2014, para 2). Furthermore, the Omnibus Budget Reconciliation Act requires that all facilities "must have sufficient nursing staff to provide nursing and related services to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident, as determined by resident assessments and individual plans of care" (OBRA 42 CFR 483.30). In addition to these broad federal guidelines, each state may set their own nursing home staffing guidelines. In Illinois, staffing requirements were most recently established by the Nursing Home Care Act, which went into effect on January 1, 2014. This particular law increased minimum staffing ratios for nursing homes providing intermediate and skilled care.[22] Nursing home residents who require intermediate care must receive a minimum of

[22] An intermediate care facility provides "health services and some nursing supervision in addition to help with eating, dressing, walking, or other personal needs" (Illinois Department of Public Health, 2016, para 36). A skilled nursing facility provides "round-the-clock nursing services available to residents who require them" (Illinois Department of Public Health, 2016, para 37).

2.5 hours of nursing and personal care each day, and nursing home residents who require skilled care must receive a minimum of 3.8 hours of nursing and personal care each day. Such regulations set nursing home staffing minimums that are defined by the minimum number of hours of care a resident should receive. In other words, rather than requiring a specific staff to resident ratio with which nursing homes must comply (e.g., 1 CNA for every 8 nursing home residents), federal and state regulations require nursing homes to have enough staff so that each resident receives a specific number of hours of care per day, and nursing homes are given the autonomy to determine how many staff they need to meet these minimum requirements of care. Thus, federal and state regulations measure care in temporal terms, and specifically measure it according to clock time.

Cedarwood Care Center's aim was to have six CNAs and two nurses per shift. There were 48 residents in the dementia unit when it was at full capacity, and it often was because there were people waiting for openings in units catering to elders with Alzheimer's and other dementias. When fully staffed, each CNA would be responsible for eight residents and each nurse would be responsible for three CNAs and 24 residents. While I always observed two nurses present, it was rare for there to be six CNAs in the dementia unit. There were typically four CNAs; however, I witnessed as low as two or three CNAs during periods of time during which there was an illness going around or there had been a heavy snowstorm. Other times, other floors would be short and so the CNAs assigned to the dementia unit would be moved temporarily to other floors. For example, if there were two CNAs on the sixth floor and four CNAs on the dementia unit, one of the CNAs from the dementia unit would be moved to the sixth floor. Or, if the dementia unit only had two CNAs, CNAs typically assigned to other floors (who were referred to as "floaters" or "loaner" CNAs) would be placed in the dementia unit. These changes would often be stressful to the CNAs in the dementia unit, as illustrated in a conversation I had with Alyia, a CNA.

> *I enter the common area. I was not here yesterday so Alyia is excited to see me. "Hello, girl!" she exclaims (her usual greeting for me). As soon as I sit down, she shares, "Yesterday there were only three of us. Six CNAs called off for the building, so only three on this floor! Karina was sent to the 7th floor, and Stella was sent to the 3rd, and they should be here. And the nurse yesterday wouldn't help us supervise. That white nurse. Said she didn't have the time! And we do?! This floor is full. 48 residents. Not one empty room. And three CNAs. That's 16 residents per CNA." Alyia sighs and shakes her head.*

At one point, moving the CNAs around due to understaffing became such a regular practice, the administration at Cedarwood Care Center implemented a new "floating" policy. The policy stated that CNAs would no longer have a permanent, assigned floor. Instead, they would be assigned to a floor when they arrived at work.

These changes resulted in each CNA having less time with the old women with dementia, and therefore, they acted as barriers to the care relationships between CNAs and residents.

> *Stella feels the administration makes policies without the input and perspective of the CNAs, and there is too much turnover in management. "They come, they make up policies, and they leave." She is upset about the new policy that no one has an assigned floor, and the administration can assign CNAs to any floor they want each shift. She feels the relationship with residents is what makes her work meaningful and worth doing. "I'm not going to float, to work another floor. I know these people, what they need, what they like. I don't know people on other floors, and they don't know me. They want their CNAs; they don't want me. And other CNAs don't want to be here. Ain't nobody wanna be here on this floor, it's so hard. It's hard work. And I ain't here for the pay, they don't pay us shit. I'm here for my people."*

Stella's relationship with the residents was her primary motivation for working as a CNA—these relationships gave her job meaning. Alyia also felt the relationships between the care workers and the old women with dementia should be prioritized.

> *Alyia is upset because the administration has decided that no CNAs will have a permanent floor. This morning Bella, a CNA from the rehabilitation unit, was sent to the dementia unit and Gladys was sent to the rehabilitation unit, but then Bella threw a fit, saying she did not want to work on "that floor"! The nurse agreed to have them switch this time. Alyia stated this policy makes no sense - it upsets the residents on all floors when their regular CNAs are not there. Alyia shared that she was sent to a different floor and residents became upset with her because they didn't know who she was, why she was in their rooms, and she didn't know what they liked and didn't*

> *like. "There is trust between the residents and CNAs but it's like [the administration], they don't care! They don't care about the relationship."*

The floating policy failed to take into account the relationships the residents had developed with their CNAs and nurses. Stella even partially blamed high staff turnover on rules and regulations like the floating policy, asserting that the job was not rewarding without those relationships. She once confided in me, “A few months ago [Cedarwood Care Center] hired 20 CNAs, and they all gone now! You got CNAs in the locker room, on their phones, searching for other jobs!” Stella felt strongly that allowing the CNAs to develop relationships with residents and supporting those relationships would be one way to address issues like staff turnover.

The floating policy also resulted in CNAs who had no interest or training in caring for people with dementia working in the unit. As Karina, a CNA, pointed out, “Not everyone has dementia training.” CNAs from other floors often openly expressed their exasperation while working in the dementia unit.

> *Four residents in the common area—Bernice, Kiska, Laurelle, and Jack—are labeled as fall risks and keep standing, often at the same time. The dementia unit was short staffed today, so there is a CNA who usually works on another floor. She rushes around the common area, trying to get Bernice, Kiska, Laurelle, and Jack to sit down and stay seated. She cries out in frustration, “What is wrong with these people?”*

These CNAs usually did not know essential information about the residents, which compromised the residents’ safety and well-being. As Gladys explained, “You can confuse [a resident] and it can escalate to a lot. She wants to run to the elevator. She tries to hit CNAs, nurses. That’s…why you shouldn’t have [CNAs from other floors] on [the dementia unit].” The CNAs on the dementia unit had intimate knowledge of the old women with dementia through connections and relationships that could only be built over time. It also seemed the floating policy, although intended to address understaffing, more negatively affected the dementia unit than other units. Apple, a nurse, explained:

> *You know, dementia or Alzheimer's patients are very challenging to take care of. And what I found at [Cedarwood Care Center], a lot of CNAs [usually assigned to other floors] don't come and work on our floor. They always complain and always resist coming on [the dementia unit]. If they know they are coming, some of them do not show up.*

The CNAs grew increasingly frustrated with the floating policy, and some started resisting being assigned to other floors.

> *There is fighting over the new CNA floating policy—people are being assigned floors they don't usually go to and are refusing to go. Brenda [the head nurse] directs them to go where they are told, and that if they think it's wrong, they will work it out later. The CNAs later talk amongst themselves about defying these directions.*

Over time, perhaps due to their resistance, the CNAs in the dementia unit were assigned to other floors far less often. However, understaffing continued to be an ongoing issue.

The CNAs nearly always started each shift asking each other, "How many are we?" or even just, "How many?"—meaning, how many staff are here? The answer would set the tone for the shift as it would often dictate how stressful work would be.

> *Gladys [a CNA] enters the common area. Tashmiya [a CNA] asks, "How many?" "Three," Gladys responds. "Three?!" Tashmiya asks incredulously, adding, "That's terrible." "How will that work?" I ask. Tashmiya shrugs helplessly and says, "Maybe the nurse will help, or maybe they will pull a CNA from another floor. I don't know. I don't know how these people will get the proper care."*

> *Trishna [a CNA] walks in and Reyna [the Activity Director] asks, "Trishna, how many are you?" "Six!" Trishna exclaims excitedly. She smiles widely and gives a thumbs up. Reyna responds, "Good! Six in the morning as well!" "And last night, we had five! But for three or four months, we only have three or four. They killing us," Trishna says. Reyna shakes her head and adds, "One weekend, two." "They are killing us!" Trishna repeats.*

When there were five or six CNAs, the staff were less stressed and could provide higher quality, more personalized care. The few times there were five or six CNAs, it was a after a major hiring fair that Cedarwood Care Center held and during the state's annual inspection. Some of the CNAs expressed resentment that they were fully staffed when being evaluated but not other times.

> *Guadalupe informs me that once again they are short staffed and only have four CNAs. Five were scheduled but another floor only had three so one of them had to move to that floor. Guadalupe shares that she feels Cedarwood Care Center is well aware of the staffing issues so there is no point in complaining. I comment that I observed they had five CNAs during the state inspection. Guadalupe responds, "See? They know what they are doing."*

Ciera was so irritated that there was more staff than usual during the inspection, she sarcastically told the other CNAs, “We should all call off tomorrow.” Although it was essential for Cedarwood Care Center to pass the inspection, the CNAs felt that if they could have more staff when the state was there, they could have more staff all the time. Although it was likely the administration was just doing the best they could in a difficult situation without enough staff, the CNAs did not believe the administration respected them or their relationships with the residents as much as they should.

Typically, there were only four CNAs for the morning and evening shifts, which meant that each CNA cared for 12 residents. When there were three CNAs (which was common for the overnight shift), they each cared for 16 residents, and when there were two, they each cared for 24 residents—a nearly impossible task. As Meera, a CNA, once said during an understaffed shift, "Someone needs to do something. What are we supposed to do? Neglect all these patients?" Having too few CNAs did not only affect the CNAs and residents, it also affected the nurses adversely. Apple, a nurse, explained:

> *It makes the job very stressful [when we are understaffed]. It makes it stressful, because that's when you start having a lot of falls and a lot of injuries. That's when you have to leave your nursing care to go and provide, uh, other care and you know, like, help the CNA give them a bath, change them, help them transfer them into bed. And then you have...and you have medication to give, you have deadlines, you have to get out of work at a certain time. And then you can't go [on break], it just becomes very stressful.*

In an interview with Ciera, a CNA, I asked her about how staffing affects her relationships with residents.

> *Hailee: What about staffing?*

> *Ciera: Yeah. Cause sometimes we're short [staffed], sometimes we done work [with] three, sometimes me and [another CNA] work the floor…so staffing is important.*
> *Hailee: What do you do when that happens?*
> *Ciera: We just get more people. [Shrugs and scoffs.] What…I mean, you do as much as you.*
> *Hailee: Just try to fit as much as you can in.*
> *Ciera: Yeah. And when we're short…I just go by safety and try to do as much as I can.*
> *Hailee: So, do you mean…you do the bare minimum of what they need?*
> *Ciera: Yes.*
> *Hailee: So, you're spending less time…talking or doing "extra" things?*
> *Ciera: Yeah, yeah. Because we have more residents.*

Although Ciera indicated that understaffing did serve as a barrier to developing relationships with residents, her answer signified that relationships are less of a concern when there are too few staff—in those cases, she just focused on doing what she could in the time that she had and tried to keep all the residents safe. Stella, a CNA, discussed in her interview the impact that having more staff and more time could have on care.

> *Hailee: You mentioned you need more time and more staff. Can you say more about that?*
> *Stella: Because if you have more staff, you can spend more time with your resident. You don't have, okay, I need to go do this and then I have to leave them here. You know each person need to get their own individual time. But when you're one person and you have got 13 other people and each of those 13 people, their dementia is in different stages than others, then that's what makes it difficult. Like it's really hard, but you have to have the patience for this job. You have to enjoy working with older people.*

Gladys, another CNA, also expressed that having more time at work would improve the care she could provide and assist her in building relationships with the residents, and the primary way she felt she could have more time was by there being more staff and a lower staff to resident ratio.

> *Hailee: What would be an ideal day or work, like from start to finish? And you can be as detailed as you'd like. Like, what would that look like if there's an ideal day?*
> *Gladys: Getting people up for breakfast, taking the time to help them eat breakfast, take them to activities, shower, bathe people. Actually, be able to help them to the bathroom when they need to go to the restroom. And…that would be [the] daily morning routine. I feel like [evenings] would be giving them…the option to go to bed when they wanted to go to bed. Not because you had the time to do it. Cause I don't know, this is where I feel like…the shifts differ. Cause mornings, it's like, you get*

> *them up, they're up. But afternoons it's like, well, it's seven o'clock, I only have time to put you to bed now, cause I have two showers to do, and I have to put this person, this person, and this person in bed before 11 o'clock [when the shift ends]. So, it's not...If I had more time in the day, I think, or less [residents]. So, if I didn't have 12 [residents] to take care of, I probably could do that if I had six.*
> *Hailee: Right. So…take more time to do things, give them more time.*
> *Gladys: Yeah, so it gives them the option to say if they want to wash their face for 25 minutes because that's their skin routine, I can give them that. But...I've told people I can't give you that, I really only have 20 minutes [from start to finish] getting your clothes off, getting you to bed, and being finished with you. Compared to if I had six people, I could give you the hour you might need.*

In a separate interview, Alice, an old woman with dementia, similarly discussed how if there were more staff, she could have better relationships with them and they could provide her with more personal care. Interestingly, she also gave the example of a more individualized evening routine.

> *Hailee: Do you think [the care workers'] jobs are hard?*
> *Alice: Oh yeah, no doubt about it.*
> *Hailee: Do you think if there were more staff, the care could be more personal—*
> *Alice: Personal, that's exactly the word…yeah, yeah, that would be helpful and then they could…put out those lights, close the door, put on socks and things like that, turn the TV on or off, say goodnight.*

Alice was understanding that there were not enough staff and she praised the care workers' efficiency, but it was clear what she truly wanted was more personalized care and stronger care relationships between the old women with dementia and the care workers. Both residents and care staff agreed with the need for more staff and perceived the connection between time and care. As Guadalupe once shared during an evening shift:

> *"We do the best we can but there's not enough time. And different people have different needs. If there are fewer [CNAs], that's less time we have [with each resident]. They all do better with companionship, with someone sitting with them, but we can't do that."*

Thus, the old women with dementia and the care workers understood care as entangled with time, which I discuss in more detail in the next chapter. Just as care was connected to time, time was connected to staff—to care for residents in the way that they wanted to, to go

beyond just meeting basic needs or ensuring safety, they needed more time, and to have more time, they needed more staff.

Understaffing was such a significant issue on the dementia unit that my very presence changed the dynamic of the unit. One of the primary ways I gained rapport with the CNAs, nurses, and other staff was through assisting them with various tasks that the administration had given me permission to do, such as transporting residents, feeding residents and refilling drinks during meals, helping ensure residents did not fall, fetching items for residents, and supporting residents during activities.[23] Over time, I was treated more and more as an "extra" staff member, as the following interactions demonstrate.

> *Alyia sees me walking down the hall and says "Oh! I need your help. I am going on my break and Sylvia is in the dining room!" Alyia's break is 12:30 pm - 1:00 pm, and it's already a few minutes past 12:30 pm. The CNAs break is only 30 minutes, so they do everything they can not to start it late. I walk in the dining room and Sylvia is walking amongst the tables. She had gotten up from her wheelchair while no one was watching. "Sylvia! Look at you out and about!" "Yes!" Sylvia says. Reyna and I get Sylvia to sit in her wheelchair. Sylvia reaches for my hand. "You're a doll. I really mean it. Not many people come." I tell Sylvia she is a doll too and she kisses my hand. I take Sylvia to the D-wing common area.*
>
> *As I get ready to leave the unit, Guadalupe and Tashmiya approach me. "You are leaving?" Guadalupe asks. "Yeah now that it is pouring rain!" I respond. "Well you should stay here then!" Guadalupe says. Tashmiya agrees, "Yeah don't put yourself at risk!" She rubs my arm protectively. "Today was exhausting," I say. "Many of the residents were upset and restless, and Margaret hit me." "Yes, that is what we deal with every day," Tashmiya says empathetically. Guadalupe says, "We need you in the evening shift!" "I know, I need to come more in the evening. All the shifts are short staffed." Guadalupe nods and says, "Write it down!" "I am," I affirm. "Good," Guadalupe and Tashmiya say.*
>
> *As I said my goodbyes to everyone at the end of my fieldwork, Ashanti told me, "I wish you to come back. We need you here, we need help. Thank you for everything you have done."*

It was often a surreal feeling to know that if I was not there, the old women with dementia would not receive the same quality of care. It placed a heavy burden on me that I was not

[23] I was not granted permission or authority by the administration or the IRB to assist with care tasks such as toileting, showering, or dressing so I never took part in these tasks.

expecting when I began my research. Although it helped me understand the CNAs and nurses' experiences, concerns about staffing, and desperate feelings for "more time" on a deeper level, it also was a source of struggle and even pain, as I knew that my presence there was temporary, and after my research ended, the dementia unit would return to its typical way of functioning with too few staff.

(Under)staffing was a central part of the economy of time at work in the dementia unit. The number of staff directly influenced how much time the CNAs could spend with each resident. Within the context of the dementia unit, the care workers were continuously distressed over their need for "more time," and having more time could only be achieved with more staff. Thus, understaffing created significant barriers for the care relationships between the old women with dementia and the care workers.

2. **Shifts and Hourly Pay**

In addition to understaffing, the care workers were also subject to institutional and bureaucratic time structures that determined the hours they worked and how much they earned per hour. Time is economized in the ways that nursing home staff, particularly nursing assistants, are compensated for their labor. In *Mastered by the Clock: Time, Slavery, and Freedom in the American South*, Smith (1997) observed how capitalism created the economic, social, and cultural belief that "time was money," and therefore, "clock time could be used to regulate, measure and exploit labor" (p. 38). Nursing home staff experience difficult working conditions with increasing levels of bureaucracy and control due to state regulations. They frequently work for low, hourly wages, and without access to benefits such as paid leave, health insurance, disability insurance, or retirement packages (Shih et al., 2014). Furthermore, there is limited opportunities for nursing

assistants to advance within an organization. Consequently, nursing home staff's time becomes exploited as they are simultaneously overworked and underpaid.

At Cedarwood Care Center, the starting pay for CNAs was $13.77 an hour.[24] One of the CNAs, Makenna, once enthusiastically shared with me, "That's high compared to some of the other nursing homes in Chicago!" But another CNA, Karina, complained that the pay was lower than another nursing home at which she worked in one of the suburbs of Chicago. $13.77 an hour for 37.5 hours a week equates to a biweekly paycheck of $1,032.75, or $24,786 a year, which is below the national median pay reported by the Bureau of Labor Statistics (2020). However, unlike some for profit nursing homes, Cedarwood Care Center provided the care staff with a generous benefits package including sick time, vacation time, medical, dental, and vision insurance, life and short-term disability insurance, and retirement plan options. The CNAs at Cedarwood Care Center were also unionized which provided them with additional protections.

Full time CNAs historically worked 40 hours a week. The morning shift was 7:00 a.m. to 3:30 p.m., the evening shift was 3:00 p.m. to 11:30 p.m., and the overnight shift was 11:00 p.m. to 7:30 a.m. This schedule included an unpaid 30-minute break for lunch and two unpaid 15-minute breaks. The 30-minute overlap between shifts allowed for CNAs to do rounds together and discuss the statuses of the residents as they transitioned caregivers. However, Cedarwood Care Center restructured the shifts so that morning shift was 7:00 a.m. to 3:00 p.m., evening shift was 3:00 p.m. to 11:00 p.m., and overnight shift was 11:00 p.m. to 7:00 a.m., thereby eliminating the 30-minute overlap between shifts. The shifts still included an unpaid 30-minute break and two unpaid 15-minute breaks, but the adjustment to the shifts resulted in full time CNAs only working 37.5 hours a week. Alyia lamented, "It's

[24] As of 2020, Cedarwood Care Center increased its starting hourly salary to $15.04 per hour. During times when they were short staffed, the nursing home offered a $500 - $1,000 signing bonus.

about $50 less a paycheck. That's a lot of money! They always make cuts that affect the CNAs, even though we do the hardest work! They didn't cut anyone else's hours! It makes you angry." The loss of $50 a paycheck equated to $1,400 a year. Furthermore, the reduction in hours affected the CNAs accruement of paid time off, since paid time off is calculated based on the number of hours worked. However, other CNAs, such as Ciera, did not mind the hour reduction, as they found the job stressful and wanted to leave as early as possible after a difficult shift.

Some CNAs and nurses also reported not taking their breaks due to being behind on their care work and documentation. When asked to describe a typical day of work, Stella, a CNA, said, “Busy. Very busy. You barely have time to go on your two 15-minute breaks, you barely have time to go on your lunch break. It's just busy nonstop.” Apple, a nurse explained that she often works through her breaks.

> *Hailee: How do you experience time at work? Like does it ever seem to speed up or slow down or standstill?*
> *Apple: My permanent shift is the 3:00 p.m.-11:00 p.m. To me, it seem like [it] goes by slowly. And because I cannot get my work done on time. Because I am constantly helping the CNAs, you know, especially A-wing of the unit. It’s very heavy with high risk fall people, people that need to be transferred constantly, that require a two person assist, so if the CNA can’t find [another CNA], of course they will come and get me. I can’t say no. Sometimes I have to help with bath, transfer them, stay in the shower room…so it slows me down. I don’t get done with [distributing medication] and sometimes I don’t even go for break. I eat my dinner at my desk. Most of the time as a matter of fact.*
> *Hailee: Wow.*
> *Apple: Yeah. They don’t understand all the sacrifices people make. But yet [the administration] still don’t pay me for 30 minutes…you clock out, they don’t pay you. Even if you don’t clock out, they won’t pay you for 30 minutes. Sometimes I just don’t clock out, sometimes to be frank, I forget to clock out because you’re not taking a break, there’s so much to do and you’re rushing and you know, I don’t take a break…so I’m the one getting screwed.*

Due to the nursing home being understaffed, the nurses and CNAs were overworked and so pressed for time that some would work through breaks, thereby providing unpaid labor to the nursing home.

As a result of the low pay, many of the CNAs worked second jobs. Tashmiya worked as home health aide. “I help an old lady three times a week in her apartment, sometimes before I come here for evening shift or sometimes on my days off,” she said. Karina worked as a CNA at another nursing home, also on her days off. “I have part time job too. I am never here on Thursdays because that’s when I am there.” Some other CNAs worked in second jobs not at all related to care work; for example, Tatiana drove for Door Dash, a local restaurant delivery service. Quite a few of the CNAs did not have second jobs, but regularly worked extended shifts and double shifts, which the nursing home encouraged due to their ongoing shortage of direct care workers. An extended shift was usually about 12 hours. A double shift was 16 hours. For example, Ashanti and Evie often worked doubles for first and second shift. They would arrive at 7:00 a.m. and leave at 11:00 p.m. Alyia commented, “How people can work doubles, I don’t know. Like Evie is doing. Multiple times a week. Maybe if you have a day off the next day but she comes in next day! But you know, you need to.” Working second jobs, double shifts, and extended shifts allowed the CNAs to earn more money, but also contributed to their exhaustion and placed them at a higher risk for injury and burnout.

The undervaluing of care workers’ labor has resulted in a form of bureaucratic and institutional time within nursing homes that is racialized, gendered, and classed. The low wages of direct care workers have been justified because their labor has been labeled “unskilled” and “menial” and their certification requires little education. The Centers for Medicare and Medicaid Services (2020) classify the work the CNAs perform as “custodial care,” or non-medical care that provides assistance with ADLs and IADLs. Custodial care is defined in opposition to what they term “skilled care,” or medically necessary care that can only be provided by skilled or licensed medical professionals. Such labels justify the underpayment of CNAs and other direct care workers. However, such reasoning obscures

long histories of racist and sexist social and cultural practices that have designated caring for others as “women’s work” that is of little value. In *Forced to Care*, Evelyn Nakano Glenn (2010) traced the history of the social organization of care, carefully documenting the ways in which marginalized women have been coerced to engage in caregiving in the United States. She argued, “The imprint of these historical formations can still be seen in contemporary patterns and practices in both unpaid and paid caring labor” (Glenn, 2010, p. 8). Throughout history, multiply marginalized women’s time and labor has not been ascribed much value, which is reflected in unpaid labor, low hourly wages, and the need to work long hours or multiple jobs in order to survive. Instead, the value of direct care workers is rooted in their exploitation, which allows long-term care facilities to remain in business and, in the case of for-profit nursing homes, earn money.

The direct care workers and all of the staff at Cedarwood Care Center were acutely aware they were being exploited through practices such as understaffing, low hourly wages, unpaid labor, and decreased work hours. The staff would often openly discuss this exploitation, as evidenced by this conversation between Tim, a Black maintenance man, and Cherise, a Black dining services worker.

> *There are only three CNAs during today’s morning shift because two CNAs are at a required in-service training. Due to the shortage I am helping even more than usual and I go into the kitchen to fetch some water for Lucille and overhear Tim, a black maintenance man, and Cherise, a black dining services worker, talking. Tim says, “Three CNAs for 47 people. Wow. Wow. They are crazy. That’s how the rich get richer, baby!” Cherise replies, “I know what you mean.” “I never had it that hard,” Tim shakes his head.*

The CNAs would also often discuss issues such as low wages with the old women with dementia, as in this example with Karina, a CNA, and Lucille, a resident:

> *A group of residents are sitting in the common area. There is a lot of commotion—many residents are feeling restless. Lucille suddenly announces, “I gotta go! This is too much for me!” Karina responds, “Me too! Can I go?” Lucille says, “This is your job, not my job.” “Well they don’t pay me enough!” Karina replies. “Oh, I’m sorry,” Lucille says. “I have your support?” Karina asks. “Yes, I’ll come back for you later!”*

> *Lucille pats Karina on the shoulder and Karina puts her hand over hers and smiles. Then, Lucille walks out of the common area.*

As illustrated in this interaction, when the care workers would discuss their low pay, the old women with dementia were often sympathetic to them. For some CNAs, the relationships they had with the old women with dementia were the reason they tolerated the low pay and difficult work conditions. Stella, a CNA, explained:

> *We come here to take care of someone else's family member which is their loved ones, and we still can't get a break. Like we underpaid, understaffed, all of that. If you [working in a] nursing home or working with anybody in a facility, especially with dementia, you can't be doing it for the money because they underpay us. But it's not about the money, it's about my people.*

The care relationships between the old women with dementia and the care workers thus served a paradoxical role. The relationships served as a source of meaning in the labor the care workers performed, yet simultaneously subjected the care workers to exploitation as gendered, racialized, classed subjects in the context of transnational capitalism (Erevelles, 2011).

3. **Daily Routines**

Care relationships between the old women with dementia and the care workers developed in the context of the daily routine. Institutional time and bureaucratic time were used to determine and organize the daily routines of the residents and care staff. A typical day for residents and care staff at Cedarwood Care Center was heavily regulated and routinized (shown in Table I: Daily Routine of Care Staff and Residents). This institutional daily routine virtually never changed, with the exception of the types of activities that were offered.

In the dementia unit of Cedarwood Care Center, the daily routine benefited the residents and staff in particular ways. For the old women with dementia, the routine generated consistency and predictability.

TABLE I

DAILY ROUTINE OF CARE WORKERS AND RESIDENTS

Time	Care Workers	Residents
5:00 a.m.-7:00 a.m.	Wake residents, toilet them, dress them, and if applicable, transfer them to their wheelchair. Transport them to the dining room for breakfast. (CNAs)	Wake up to get ready for the day.
Morning Shift: 7:00 a.m.-3:00 p.m.		
7:00 a.m.-8:00 a.m.	Serve all residents food, and feed residents who require assistance. (CNAs) Distribute medication and assist as needed. (Nurses)	Eat breakfast.
8:00 a.m.-8:30 a.m.	Transport residents from the dining room to the common area in one of four wings. (CNAs)	Sit in the common area and watch TV.
8:30 a.m.-9:00 a.m.	Toilet residents, shower residents, change linens, make rounds, etc. (CNAs)	
9:00 a.m.-9:30 a.m.		Exercise class led by a physical therapist. (“High functioning” residents only.) Sit in the common area and watch TV. (All other residents.)
9:30 a.m.-10:00 a.m.		Sit in the common area and watch TV.
10:00 a.m.-11:00 a.m.		Monday-Thursday: Karaoke, music, or similar activity. Friday: Kiddush, the Jewish tradition of having a ceremony and blessing to usher in the Sabbath.
11:00 a.m.-11:30 a.m.	Transport residents from the common area to the dining room. (CNAs)	Get ready for lunch.
11:30 a.m.-12:30 p.m.	Serve all residents food, and feed residents who require assistance. (CNAs) Distribute medication and assist as needed. (Nurses)	Eat lunch.

TABLE I (CONTINUED)

DAILY ROUTINE OF CARE WORKERS AND RESIDENTS

Time	Care Workers	Residents
12:30 p.m.-1:00 p.m.	Transport residents from the dining room to the common area in one of four wings. (CNAs)	Sit in the common area and watch TV.
1:00 p.m.-2:00 p.m.	Toilet residents, change linens, make rounds, etc.	Small group activity. ("High functioning" residents only.) Sit and watch TV. (All other residents, in separate wing.)
2:00 p.m.-3:00 p.m.		Monday-Friday: Activity such as music, sing-alongs, hand massages, classic movie viewing, trivia, etc. Saturday: Services for the Sabbath were held in the Synagogue.
Evening Shift: 3:00 p.m.-11:00 p.m.		
3:30 p.m.-4:00 p.m.	Do rounds at start of shift, toilet a few residents.	Watch Jeopardy.
4:00 p.m.-4:30 p.m.	Transport residents from the common area to the dining room. (CNAs)	Get ready for dinner.
4:30 p.m.-5:30 p.m.	Serve all residents food, and feed residents who require assistance. (CNAs) Distribute medication and assist as needed. (Nurses)	Eat dinner.
5:30 p.m.-6:00 p.m.	Transport residents from the dining room to the common area in one of four wings.	Sit in the common area and watch TV.
6:00 p.m.-7:00 p.m.	Toilet, shower, and change residents to prepare them for bed. Aid residents in transferring into their beds. (CNAs)	Activity such as stretching or chair dancing 1-2 times per week. Otherwise sit and watch TV.
7:00 p.m.-9:30 p.m.		Go to bed and sleep.
7:00 p.m.-11:00 p.m.	Do regular rounds to check on residents and see if they need assistance. (CNAs and Nurses) Toilet residents as needed. (CNAs)	Sleep.

TABLE I (CONTINUED) DAILY ROUTINE OF CARE WORKERS AND RESIDENTS		
Time	Care Workers	Residents
Overnight Shift: 11:00 p.m.-7:00 a.m.		
11:00 p.m.-5:00 a.m.	Do regular rounds to check on residents and see if they need assistance. (CNAs and Nurses)	Sleep.

It has been well established that routines are generally beneficial for old people with dementia, as the regularity provides a sense of security and reduces confusion and anxiety (Harmer & Orrell, 2008). The few times the routine did change, some of the residents experienced the change quite intensely, as evidenced by this interaction I had with Alice, an old woman with dementia, during lunch:

> *I enter the dining room and Alice gestures at me urgently to come over. I approach her and greet her and ask her how she is doing. "Not good," she responds. "Not good at all! First of all, I have barely seen Reyna [the activity director] all day! And that really disappoints me. And the man who leads our morning exercise class, this man will be gone three days this week on vacation, and no one will be filling in for him, and now we will miss three days of exercise! You are the researcher, right?" "I am," I respond. "Can you investigate these things for me? What is going on?!" I tell her I will ask around and try to find out what is going on. "Thank you. Thank you!" she responds in an anxious, high-pitched voice.*

Alice's distress at the change in routine was palpable. It is important to note that Alice was not just upset about the alteration to the daily schedule, but also a change she perceived in the care staff's schedules, which she expected to align with the daily routine in a specific way.

Apple, a full-time nurse on the dementia unit, explained how important it was for the old women with dementia to have a consistent daily routine with regular and reliable care staff:

> *Apple: Only the [CNAs] that are permanent—they're the ones that will show up when it's their time to work.*
> *Hailee: I've definitely noticed that the permanent staff are consistent.*
> *Apple: But when they're sick or on vacation, then it makes it difficult. [People with dementia] have to know their routine, you know, and you just have to be consistent, you have to be consistent, they want to see a consistent face. Even though they have dementia…a lot of them know me, are aware of the permanent nurses that are*

> *on there…so when you come in contact with them, they are not afraid, you know, but I noticed that strangers…they can be resistant to strangers…because I guess they think you coming to hurt them or abuse them, so, so it makes it difficult. Like when some [nurses from other floors] worked [the] 7:00 a.m.-3:00 p.m. shift, I come and they say, oh, this person didn't take their meds, that person didn't take their meds, and you know, and I will go and give them the meds and they will just take it easily. If they are not used to you, they don't trust you.*
> *Hailee: So that relationship is really important.*
> *Apple: It is very important for a dementia unit.*

The dependability of the care staff allowed the residents to build relationships with them and made them feel safe and reassured. Thus, the rigidity of the routine and the consistent presence of care staff was important to the well-being of many of the residents, and institutional and bureaucratic time in this context became source of predictability and security.

Additionally, the daily routine provided structure for the care staff to complete their work. As noted by Heerema (2020): “Routines can lessen the stress for those caring for people with dementia by making the day more organized” (para 10). Institutional time and bureaucratic time served as a way to ensure care tasks were carried out. Care workers were responsible for a significant number of tasks and had to complete these tasks with each resident. As one CNA, Stella, noted, “You have to do everything. You have to change them, you have to feed them, you have to bathe them, you have to do everything.” As part of their job requirements, CNAs showered residents, toileted residents, dressed residents, assisted in personal and dental hygiene, distributed drinks and snacks, transported residents and assisted in ambulation, transferred residents into beds and wheelchairs, changed linens, answered call bells and made rounds, took and recorded vital signs, set up oxygen tanks, monitored residents labeled as “fall risks,” and documented all care provided. Nurses evaluated residents and monitored health conditions, administered medications, coordinated care, communicated with doctors, supervised and assisted CNAs, and documented all medicine administered and care provided. This work occurred in addition to

emotional labor and responding to the residents' changing needs. Therefore, the daily routine created a process that ensured the care staff could complete their required care tasks (or come as close as possible to achieving this goal given understaffing, resident turnover, and constantly changing resident needs).

CNAs and nurses at Cedarwood Care Center often constructed their own complex routines to ensure everything was completed within the restrictions established by the institutional routine. Below is an excerpt from an interview with Ciera, a CNA, in which we discussed how she cares for residents within the confines of institutional time and residents' individual needs.

> *Hailee: What would be an ideal day of work, from start to finish?*
> *Ciera: Well, when I get here at 7:00 a.m., we go right in the dining room and serve breakfast. It depends on…the overnight [shift], it depends on if...they were short overnight...we have to get up more people. But if it's the right amount [of staff overnight], if it's four people, it's kind of a little easier because a lot of people's in the dining room. So, like I said, when we come, we serve food. I feed two residents now. And then after breakfast, I go get up one resident, getting him ready for exercise. And then I bring [all the residents] to the common area, I sit down for 30 minutes and watch them. After 10:00 a.m., I start toileting my people and gettin' them ready for lunch. And then after lunch, we go back to the common area and watch a movie. And then after 1:00 p.m., I change one or two people that I hadn't changed.*
> *Hailee: So, how do you organize when you're changing people, or doing showers, or the stuff you need to do like shaving someone or—*
> *Ciera: Well that's easy. I shave Bernard on Wednesdays and Sundays. Because that's his shave and shower day. [My group of residents showers] on Wednesdays and Sundays and Thursdays and Mondays. So I know...to come up here a little earlier on those days, and feed the people, and get started. So then I do my shower for one lady, her daughter comes at 8:30 a.m. [to help], so she has to be done by 9:30 a.m. because [the daughter] has to go to work. Bernard, I have to just do him by 10:00 a.m., since his family meets him...for Bingo. So, it's just different days. Or if they have services or they need to be up or if they have an appointment.*

Ciera described this routine as "easy," although it was quite complicated—changing day to day and dependent on her residents' changing needs and their families' schedules. Even as she explained her care routine, she had trouble doing so chronologically because it was complex yet also so familiar to her. Ciera had to conform to institutional time (for example, she had to serve and feed residents during mealtimes, which occur at the same time every

day) while also creating her own routine around institutional time that ensured all her residents' needs were met. This routine also had to conform to bureaucratic time as she was responsible for ensuring all care tasks were completed for each of the residents during her shift.

However, the rigidity and inflexibility of the daily routine also created numerous issues and challenges in the dementia unit. In an effort to improve quality of care and counter the institutional nature of nursing homes, long-term care facilities have been mandated by federal regulations to provide "person-centered care" (Maslow, 2013). As previously discussed, person-centered care, also sometimes referred to as patient-centered care, aims to prioritize the needs and preferences of the individual receiving care rather than the needs and preferences of those administering care (Kitwood, 1997). Yet delivering person-centered care, particularly to people with dementia, has proven to be challenging. Obstacles include issues such as lack of training and support for direct care workers, stereotypical attitudes toward residents with cognitive disabilities, and administrative policies and practices that do not support person-centered care (Clissett et al., 2013). Within Cedarwood Care Center, the major barriers I observed to person-centered care were understaffing and the need to care for a significant number of people with a limited number of care staff in a specific amount of time can make achieving this goal difficult.

Cedarwood Care Center highlighted patient-centered care as central to their mission. However, institutional time created many barriers that often prevented the nursing home from providing it to their residents, despite many of the care staff and administration trying their best. Gladys, a CNA, shared, "They say there's this thing called patient-centered care. I don't know if you've heard about it, but it comes up a lot [at Cedarwood Care Center]. But it's not there. You can say it all you want. But you can't give patient-centered

care with no time to give it." Apple, a nurse, also observed that the lack of time made it more difficult to provide patient-centered care:

> *Working there for a year now, I get to find out who likes what. Somebody like Manya, she likes to play with dolls. And, you know…somebody like Jung, Jung likes to help, with pushing the other residents [in their wheelchairs], you know, getting engaged in activities, you know, but we don't have staff for that, we don't have time, it's 8 hour shift, 48 patients, 4 CNAs, 2 nurses, we don't have time for all of that.*

Throughout the day, care staff engaged in numerous care tasks that had to be done around the routine established by institutional time—which, in combination with understaffing, made them constantly feel pressed for time. As Green (2017), a former CNA in a skilled nursing home, wrote, "The relentless pressure to [care for] the patients fast and adhere to the nursing home routine at all costs was dehumanizing to patients and staff" (para 15). Care staff experienced immense stress trying to care for all of the residents while conforming to the daily routine.

Another significant issue was that the strict institutional routine at Cedarwood Care Center did not account for the unpredictability of care work. Any needs that occurred that did not align with the daily routine were often not dealt with until it was the "appropriate" time, with "appropriateness" being determined by institutional time. Consequently, anything that forced deviation from institutional time was frequently a source of stress for the old women with dementia and the care staff. For example, the CNAs tried to always toilet their residents before and after meals because if an old person with dementia wanted to use the bathroom or had an accident during a meal, the CNAs were often unable to take her and if they did take her, it put them behind on the other tasks they needed to do during the hour set aside for meal times.

Relatedly, the CNAs were always under pressure to feed all the residents who needed assistance with eating in the hour allotted for meals. If residents had any issues eating, they were at risk for not receiving enough food because the CNAs only had a limited

amount of time to ensure all of the people for whom they cared received adequate hydration and nutrition.

> *Penelope is sitting with me on her right and Sophea's granddaughter on left. She becomes fixated on feeding us, constantly offering us food and taking it off her plate and putting it on the table in front of us. We keep reassuring her we aren't hungry and encouraging her to eat but it doesn't help. Towards the end of lunch, Alyia walks by and notices that essentially all of Penelope's food is on the table. She sits down next to Penelope and tries to feed her the rest of her food, but Penelope won't stop talking and vocalizing. Alyia keeps telling Penelope to stop talking and eat. "No talk. Don't talk. It's lunch time. We talk later. Eat." Alyia commands. Penelope keeps trying to talk and Alyia keeps commanding her to be quiet and eat—lunch is almost over and Penelope is running out of time.*

It is striking that, due to institutional time, Alyia viewed the purpose of the lunch hour as solely for ensuring the residents were eating and drinking. As she told Penelope, there was no time to talk and connect with others, despite that being a core part of meals outside of institutions for much of American society. I also observed that when I assisted by feeding a resident, I was able to approach it in a different way than the CNAs because I had a full hour to focus on one person, as in this example with Sylvia:

> *Sylvia is not swallowing her food well. She "packs" the food in her mouth. I request extra gravy to make her pureed food as wet as possible. I give her extra juice, wait longer between bites, and keep checking to make sure there's not too much food accumulating in her mouth. It takes me almost an hour to feed her like this. The CNAs do not have time to do this. Sophea's caregiver comments that lately, if I am not there, Sylvia's mouth has been packed with food and the CNAs just keep trying to feed her because they are in such a rush and have multiple residents to feed. Sylvia's "special needs" have become too "special."*

Thus, the rigidity of institutional time did not account for the old women with dementia's changing needs and capacities.

It also did not account for the accidents and emergencies that frequently occur in dementia units of nursing homes. A particularly harrowing example of this occurred one night during dinner time:

> *Nina's family came to visit her before dinner and brought her some of her favorite Russian foods. However, she is still taken to dinner and served food, as that is protocol—every resident must be served regardless of whether they eat or not.*

> *Mischa's private caregiver finishes feeding Mischa, so she feeds Nina as well, unaware that Nina has already eaten. As Nina is nonverbal, she cannot tell Mischa's caregiver that she is full. Instead, she eats the food the caregiver offers. After she finishes all of the food, the caregiver returns to sit with Mischa. A few minutes later, Nina vomits the entirety of her dinner. It is all over her clothes, her wheelchair, the hoyer strap she is sitting on, and the floor. The stress from the CNAs is palpable. Trishna comes over and sighs heavily. She puts on gloves and wipes Nina down as best she can, but Nina needs a shower and a change of clothes. However, because Trishna must feed other residents before dinner ends promptly at 5:30 p.m., Nina will not get either until after dinner. So, Nina just sits there, waiting, occasionally moaning and crying.*

This situation was one of the times in the dementia unit when I felt most helpless—Nina desperately needed care, yet no one was able to provide it right then and there. Although this was one of the more extreme examples, it signifies how difficult it was for care staff to work outside of the confines of institutional time when needed.

4. **Waiting for Care**

At Cedarwood Care Center, the hegemony of institutional time had an impact not only on the care workers, but on residents as well, contributing to a shared phenomenon of perpetual waiting. Rather than allowing individuals to choose when to wake up, have a shower, go to the restroom, get dressed, eat meals, or go to bed, institutional time dictates when these aspects of bodily care will occur, and is often characterized by long periods of waiting for care. As Wiersma and Dupuis (2010) observed in their ethnography of a nursing home, "Residents became aware…that staff had many residents to care for, and that they were not the only ones with care needs. This message was often conveyed through waiting for care" (p. 285). I observed residents waiting anywhere from five minutes to over an hour for various forms of care. The need to wait was also exacerbated by high staff to resident ratios and understaffing. During my time at Cedarwood Care Center, staff were constantly communicating to residents that they "had to wait." Residents were often told to wait when

their individual preferences for their personal routine did not align with the institutional routine, as illustrated in this situation with Fauna:

> *Fauna is getting frustrated in the common area. Wheel of Fortune is over, and she wants to go to bed. Her assigned CNA is with another resident, so she has to wait. Fauna gets more and more restless, and finally complains to Lulu, a nurse. Lulu tells her she is busy, but Fauna can wait for her CNA in her room. Fauna wheels around in circles in the common area, unable to get into bed by herself or when she wants. "I wanted to go to go to bed at 7:00 pm and they won't let me!" she cries. Another CNA, Tashmiya, explains, "They're busy, Fauna, that's why." "Oh," Fauna responds, dejected. She sits with her face in her hands.*

Alice, an old woman with dementia, shared a similar experience to Fauna, stating:

> *"Tashmiya, I like. She helps me get to my room, and that's another funny thing…I'm not allowed to go to my room [after dinner]. And so Tashmiya has to take me, so if she doesn't take me, then I'm in trouble. I mean, it sounds like a minor thing, but we are all looking for somebody and then nobody will take me, so…I have a serious problem."*

Alice was essentially referring to competition for care—all of the residents were "looking for somebody" to have their needs met, otherwise they knew they would have to wait. Alice would try to have Tashmiya, her usual CNA, take her right after dinner because she knew once Tashmiya became busy toileting, showering, and dressing other residents for bed, it would be harder to have her request to go to her room met.

The need to wait also frequently occurred when the old women with dementia's bodily needs did not align with the institutional schedule, particularly bathroom needs, as evidenced by this conversation between Laurelle, an old woman with dementia, and Trishna, a CNA who was not assigned to her and unable to take her due to her own responsibilities:

> *Laurelle: I have to go to the bathroom.*
> *Trishna: You have to wait. She's coming.*
> *Laurelle: Who?*
> *Trishna: I don't know their name. [Referring to a CNA who usually works another floor.] She's coming. She's busy, okay?*
> *Laurelle: I have to go!*
> *Trishna: I know. Keep sitting. Someone's coming.*
> *Laurelle: How long?*

Trishna: 10 minutes. You have to wait.

Waiting often caused distress for the old women with dementia, particularly when they needed to use the bathroom. It also led to them having more accidents, as in this situation with Isabelle:

> *Isabelle is sitting in the common area when she urgently announces, "I need to go!" Ciera [a CNA] responds, "Just stay here for a bit." "It's coming out!" Isabelle exclaims [referring to her waste]. "What's coming out?" Ciera asks. Isabelle becomes increasingly frantic. "It's coming out! It's coming out!" "Okay-" Ciera says. Isabelle interrupts her, "I need to go! It's coming out!" She is becoming more and more distressed, on the verge of tears. Now understanding Isabelle wants to go to the bathroom, Ciera tells her, "Okay, I will tell Stella [Isabelle's assigned CNA]." Ciera is in the middle of another task and cannot take her. "Who?" Isabelle asks. "I'll tell the girl that's helping you. But she's helping someone else now. So, you have to wait honey."*

In such cases, waiting frequently resulted in residents who were typically continent going to the bathroom in their incontinence briefs, which deeply upset them, compromised their dignity, and also put them a higher risk for skin infections and urinary tract infections. For residents who were incontinent, they often had to wait to have their briefs changed. The need to wait to have even the most basic needs met was a core part of socializing the residents into institutional time (Wiersma & Dupuis, 2010). Being forced to wait was distressing and debilitating to the old women with dementia, but there was little that could be done to meet their needs immediately at all times.

The CNAs and nurses also had to wait to meet their own needs when work became especially hectic. The CNAs were on a strict break schedule established by bureaucratic time, but some would report going on break late and losing needed time to rest and decompress. The nurses similarly reported occasionally delaying breaks, or as previously mentioned, working through breaks. In these moments, CNAs and nurses would weigh their own needs against the needs of the residents.

> *At lunch, Alyia sits down to feed Nina and comments how she has been going nonstop since 7 a.m. "My feet are killing me, and I haven't even had time to go to the*

> *bathroom!" Stella tells her, "You need to make time! They gotta wait because that's not good for your body either."*

Each day, the care workers had to navigate difficult decisions of when to prioritize their own needs or the needs of their residents.

Additionally, families and private caregivers often tried to demand immediate care for their relative or client. Like the residents, they were also frequently told they needed to wait.

> *Isabelle's daughter comes out of her room. "Hi," she greets Serena, a CNA, "Is there someone who can change my mom?" "I can at 3:30 p.m., in 10 minutes, when I'm done watching [the residents who are at risk of falling]. "Okay, well, she is on the toilet now," the daughter replies tersely. "Someone would have to relieve me; I can't leave these people. If not, I can't do it until 3:30 p.m.," Serena responds apologetically. "Well, I'll go find someone because I can't wait that long." The daughter returns with another CNA, Tashmiya, who volunteers to ensure no one falls while Serena helps Isabelle in the bathroom.*

> *Gelya's formal caregiver is waiting for Evie to come and put Gelya to bed, as she is not allowed to do it due to nursing home regulations. However, Evie is caring for another resident. The caregiver presses the call button in Gelya's room, frustrated. Evie comes over and asks her to turn it off, as she knows Gelya is waiting and she will get in trouble if she lets a call light flash and ring for too long. "Well we've been waiting a long time!" the caregiver retorts, clearly annoyed. "Yes, but you're not the only one!" Evie responds. Evie resumes caring for the other resident and comes to Gelya's room after she is finished.*

The CNAs and nurses appreciated that families and private caregivers were trying to advocate for their loved ones and clients, but also felt that the families and caregivers did not have a realistic understanding of their situation and how understaffed, overworked, and pressed for time they were. Apple discussed the pressure families placed on the CNAs and nurses to provide immediate care and prioritize their loved one:

> *Hailee: Do you think there's any other…changes that would help you and…better support your work, your ability to care for the residents?*
> *Apple: I think sometimes family makes it difficult. Some of them are very overbearing. Like this one family, we were having a discussion with the other day, and we tried to explain to them, now listen, we have...[each] CNA has 12 patient[s], I have 24, I oversee 24 patients and 2 CNAs, so you don't expect me to be somewhere when you snap your fingers. It is impossible for me to be somewhere when you snap your fingers. If I come somewhere, I want to come, do what I have to do, and get the hell out because I have other things to do, I have other people to take care of. And you know, especially when the family expect that you should just*

> *give all your time to their family members. We all love our family members, but we have to be open minded. And…know that it will never be 100%. That's the bottom line. I mean, that's just how it is. I can only do my best.*

The CNAs and nurses frequently shared their workload (i.e., their caseload or the number of residents they needed to care for) with families in order to help them understand why they were unable to meet their requests for care right away.

> *Sophea's daughter comes to visit during lunch and is upset her mother has not been served food yet. She confronts Ashanti. "I have seven residents to serve at this table. Your mother is not the only one," Ashanti responds firmly. The daughter apologizes, "I'm sorry, I didn't see." Ashanti's voice softens and tells her it's all right.*

By sharing the staffing ratios, the CNAs and nurses were trying to communicate with the families how many people they needed to care for and how pressed for time they were. They wanted the families to understand that their inability to meet the family's requests right away was due to the pressures of institutional and bureaucratic time, rather than a lack of concern or desire to help.

Some families became aware of the regulations established by institutional and bureaucratic time and used these standards to demand more prompt care.

> *A nursing home regulation is for residents to be toileted at least every two hours. Today there is a CNA from another floor assigned to care for one of the old women with dementia, Eva. She is having a little trouble adjusting because there are only four CNAs today and she is not used to working with old people with dementia. Eva's daughter is angry that the CNA did not come and toilet her mother after exactly two hours. The nurses, Brenda and Hannah, come in and tell the loaner CNA she needs to go take care of it right away to avoid a conflict. The CNA explains, "I had to eat lunch [during my scheduled lunch break] and then I had to watch [the residents who are fall risks]—" Hannah interrupts and says, "I know, but families don't understand this or that, it does not need to be done every two hours on the dot, but they think it does, so you must go do it."*

The CNAs and nurses typically followed the rules and regulations as much as possible, but the lack of time made it more difficult to comply and meet care needs strictly "on time." Other families disregarded or even pushed against the regulations when those rules and

guidelines did not reflect what they wanted for their family member and when they felt their family member should be assisted immediately. Apple, a nurse, noted:

> *[Families] expect you to make…their family, the number one "to do" every day, to meet all of their needs. Absolutely not, all of their needs cannot be met. And you know, and there are rules and regulations [all people in the nursing home] have to follow. [The families] do not want to follow those rules and rules and regulations.*

Although CNAs and nurses often pushed back against families' demands for instant care by citing regulations and emphasizing understaffing, there were times when they acquiesced to avoid complaints or conflicts.

The requests and demands for instantaneous care from the old women with dementia and their families were often racialized and classed, as white Jewish middle- and upper-class families[25] were more likely to demand timely service from CNAs and nurses of color, many of whom were immigrants and low-income. As a Black American woman, Ciera shared with me that she often felt the residents and families treated her like "the help."

> *Hailee: How do you sense that [residents and families are treating you like the help]?*
> *Ciera: You know, they like, "Go get this, go get that, do this, do that," even the family members. So, I feel like…they feel like CNAs are beneath us. [To them], all we do is clean ass, excuse me. So yeah. And…they look at us, or you know, think like, we're nothing.*
> *Hailee: So, they look down on you?*
> *Ciera: Yeah, down. That's the word. You know, I done have people say, "you people" and it's like, you people what? Black people? CNAs? Like you know, and I had a lady tell me like all you gonna do is clean ass for the rest of your life. And she was upper class, a lady from Highland Park. You know, they had help. Like, nobody ever told her no. So, it's hard.*

Gladys, a Black American CNA, similarly observed that there were times they felt residents and families viewed them as servants, especially if they came from a wealthy background and had employed servants in the past, and this racialized, gendered dynamic undergirded

[25] It is important to note that not all residents at Cedarwood Care Center were from white, middle- or upper-class backgrounds. A significant number of residents were marginalized by race, class, and/or immigrant status. See Chapter III: Methodology and Methods for more details about the demographics of the participants.

demands for prompt care. The CNAs often resisted this dynamic. As Ciera once told me, “There is no class in the dementia unit—everybody has to wait.”

Other care workers felt that there was much less racism at Cedarwood Care Center because there were a significant number of Jewish residents. Stella, a Black American CNA, told me, “Obviously [the residents] are not racist because this is a Jewish facility, know what I mean?” Stella and some other care workers felt that the Jewish residents were sympathetic to the struggles of women of color due to their own histories of persecution. Lucille, a white Jewish old woman with dementia told me she wanted there to be diversity at Cedarwood Care Center. “I want some of the people to be Black, I want some to be Jewish, I want some to be not Jewish. And I think it’s all the qualification of a mixed bureau…I probably treat [the Black care workers] a little bit nicer than I do the white ones because I feel that…maybe they don’t get that feeling of being here and they’re probably on the lookout for people that don’t qualify them [as] working good.” Hence, the cultural context at Cedarwood Care Center was incredibly complex, with multiple histories of oppression, violence, and exploitation interacting in the present to affect how care workers, old women with dementia, and their families understood the temporal aspect of receiving care.

In the dementia unit, institutional and bureaucratic time created a context in which old women with dementia and care workers struggled to have their needs met and often ended up waiting. Time was scarce, and as a result it was inevitable for there to be delays in providing and receiving care. Waiting was a site of constant struggle between the old women with dementia, their families, and the care workers. Waiting signaled to the residents and their families one of the core limits of institutional care—it is impossible for needs to always be met as soon as they arise. For the care workers, waiting was the inevitable outcome of understaffing, high staff to resident ratios, and residents with increasingly complex health, social, and personal needs. As noted by Brueggemann and

Brewer Olson (2019), “Disability is often a weighty matter and a matter of waiting” (para 1). Disabled people are forced to wait for medical treatment, for accommodations to be approved and implemented, for access to home and community-based services, for enrollment in Social Security Disability Insurance, and, in institutional spaces, for care.

5. **Watching/Being Watched**

Another key aspect of institutional time and bureaucratic time was a required care task that the CNAs, nurses, and administration referred to as “watching” or “supervising.” The dementia unit had a significant number of old women with dementia who were labeled as “fall risks.” Every resident who was admitted to the dementia unit underwent a fall risk assessment, which seeks to determine how likely a resident is to experience a fall. Being labeled as a fall risk is intricately connected with disablement. According to the Illinois Council on Long-Term Care (2000), people at high risk for falling in nursing homes are “those having poor vision, gait disturbances, weakness, cardiovascular disease, incontinence, and a history of falls” (para 19). Dementia in and of itself is considered a risk factor for falls (Van Doorn et al., 2013). This broad categorization included a significant number of the old women with dementia in the dementia unit. Many of the residents received the label of “fall risk” when they first arrived but I also observed the label being assigned to residents when they acquired new impairments or when existing impairments progressed.

The number of people categorized as fall risks in the dementia unit was considerably higher than any other floor in Cedarwood Care Center. Consequently, the dementia unit engaged in a practice unique to their floor: “watching” or “supervising.” Watching involved transporting all of the residents who were labeled as fall risks to the common area in one of the four wings. Between 15-30 residents would be grouped together in this common area,

and the CNAs would take turns watching them, usually in increments of 30-45 minutes, depending on the number of staff. The CNAs would watch two times each shift. The CNAs' main task while they were watching was to ensure no residents fell. During supervision, the CNAs would also make conversation with residents, provide residents with affection, distribute drinks and snacks, assist residents who were trying to remove or had removed their clothes or shoes, fix residents' hair, and document (i.e., update the residents' records by detailing the care the CNAs provided).

But their main task, at all times, was to prevent falls. Failing to do so could result in injuries or even death for the residents and consequences for the CNAs, as I learned one morning after there was an "incident" while Alyia was watching.

> *This morning while Alyia was watching, Laurelle was restless so Alyia was helping her walk around the common area. Laurelle suddenly announced, "I can't anymore!" She then tried to sit down right then and there. Alyia was unable to stop her or keep her up, so she held on to Laurelle so that Laurelle sat on the floor slowly and was not injured. Bonnie, the nurse, wants to document the incident as a fall, but Alyia protests, "No! It's not a fall. She sat down of her own accord. If I am walking and I can't walk anymore so I sit down, that's not a fall!" Aurora, the other nurse, interjects that Cedarwood Care Center wants them to document any changes in position, but Alyia insists it should not be documented as a fall and storms off. I ask the CNA who is currently watching, Serena, why Alyia was so upset. Serena explains that if a resident falls on a CNA's watch, there is a report and an investigation. If the administration finds that the fall is the CNA's fault, they may write them up, suspend them, or even fire them. Serena said they once had a Director of Nursing at Cedarwood Care Center who would walk around and yell at the CNAs and fire them outright if a resident fell. Many CNAs were quitting because the Director of Nursing was terrorizing them. Serena observes, "He may have had the education, but he'd never done the [CNA] job and he didn't know how hard it was." The current administration is more understanding, Serena reports, but falls are still considered a huge issue and can be catastrophic for the residents and detrimental for the CNAs too.*

Falls are dangerous for old people and the old people with dementia were at a greater risk for injuries or even death from repeated falls (Van Doorn et al., 2003). Falls also carry consequences for the CNAs, including reprimands, reduced pay, or even job loss. In this sense, the CNAs were watching but, like the residents, also being watched. Administrators

were well aware that if wrongdoing is found on the part of the care workers or the facility, falls can open nursing homes up to lawsuits or fines. Given this, fall prevention was a primary area of focus for the administration. At the core of watching was surveillance and control, deployed under the guise of safety. In nursing homes, there is no "dignity of risk;" institutionalized old people with dementia are legally labeled as incapable of decision-making and the legal and financial repercussions of permitting risk are high (Ibrahim & Davis, 2013).

Watching was connected to temporality in several ways. First, it further contributed to the old women with dementia needing to wait for care. The CNAs were not permitted to leave the common area while they were watching. Residents would often request to go to the bathroom, but the CNAs were unable to take them. At times they would be able to find another CNA who could assist the resident or watch in their place, but for the most part the old women with dementia were just told they had to wait. While watching, CNAs also could not fetch items for residents, help residents find their rooms, or take residents to their rooms if they wanted to rest. The inability to assist residents when they needed it greatly frustrated some of the CNAs. Occasionally, CNAs would decide to resist "watching," and help the residents who needed assistance urgently, as in this example with Stella:

> *The residents are sitting in D-wing. Isabelle, who is in her room, suddenly starts crying out, "Help! Help!" Stella is watching, and she cracks open Isabelle's door while still scanning the common area to ensure no residents are at risk of falling. "Miss Isabelle, are you okay?" Isabelle had been using the bathroom but realized she could not stand up on her own afterward. "Help! Help me!" she cried again. Stella went in to assist her. When she came back a few minutes later, she shared, "Isabelle was on the toilet…and couldn't get up. So, I helped her. Because she needed it! But if someone out here would have fallen, that woulda come back on me because I'm supposed to be watching. And that's messed up because Isabelle needed help now!"*

If the CNAs did make the decision to assist a resident rather than watch, and a fellow CNA or supervisor noticed, they were reprimanded.

> *Betty keeps asking to use the bathroom. There is a loaner CNA watching, and she does not know what to do. I leave the common area to alert Betty's CNA, Karina, but she is in the middle of assisting another resident. "I took her at 10:00 a.m. I will take her, but not right now," she tells me. I return to the common area and tell Betty someone is coming, but Betty continues to ask to go repeatedly so the loaner CNA takes her to the restroom. Ashanti comes into the common area and finds the CNA in Betty's bathroom. She scolds the CNA. "Are you even watching? Someone is going to fall!" "I am, but she had to go to the bathroom!" the CNA says defensively. Feeling she has no choice, she brings Betty back to the common area, but Betty did not have time to relieve herself in the short time she was in the bathroom, so she continues begging to go. Karina finally comes but takes a resident who has not been toileted as recently as Betty. The loaner CNA interjects that Betty has to go. "I know, but I took her at 10:00 a.m., she has to wait," Karina explains, trying to stick to her schedule. At this point Betty is becoming hysterical. "Take me! It hurts, it hurts!" Betty starts moaning so Katja takes her to the bathroom. The loaner CNA shakes her head in frustration.*
>
> *Bernice keeps standing and will not sit down. Kylie, who is watching, keeps trying to get her to sit and stay seated, but to no avail. Kylie decides to take Bernice to the bathroom—she is convinced that is why Bernice is standing repeatedly. Her instinct is right, Bernice's adult brief needed changed badly. Kylie changes Bernice and then returns Bernice to the common area, and then goes back into the bathroom to clean up. Brenda, the head nurse, enters the common area and just as she does, Bernice stands again. Brenda scolds Kylie, "What are you doing? You are supposed to be watching!" Kylie is clearly upset. "I just changed Bernice and I was just cleaning up and washing my hands." "No!" Brenda says sternly. "You need to be out here! It's your job to make sure no one falls." Brenda pauses, and then adds, "And entertain them." Kylie rolls her eyes. "I can't even take care of people, which is my job, and then she tellin' me to entertain people, which is not my job!" she complains.*

The singular focus on fall prevention was difficult to navigate for the CNAs. They understood the importance of preventing falls but were frustrated by their inability to immediately assist the residents in other ways, particularly toileting.

Second, watching reduced the amount of time CNAs had to complete all their tasks. As they were already pressed for time, some of the CNAs felt watching was preventing them from doing other important, required tasks. Alyia explained:

> *"I hate supervision the most. Because the whole time, I am just thinking about everything I need to do and everything I could be getting done during this time. Supervision takes up too much time! They didn't use to do it until four years ago [as falls increasingly became a concern], and I get why it's good, but they cut our hours from 8 hours to 7.5 hours a day [when they shortened the shifts], and we have to supervise one to one and a half hours a day, so then I have to rush to get everything done! And it's all the rushing that makes me so tired."*

Alyia and some other CNAs experienced watching as a “waste of time”—it was a task they were forced to do that inhibited them from doing other care tasks. They understood the purpose of supervision but did not feel it was a priority over other tasks such as toileting, showering, dressing, changing linens, monitoring residents’ wellness, and documenting.

Third, many of the CNAs believed that watching such a large group of residents and preventing all of them from falling was futile—there was no way they could reach every resident who was at risk of falling in time to avoid an accident or fall. Apple shared, “[The administration] are very concerned about falls. We have a lot of falls on our floor. And I remember when [a former floor manager] was there, she was trying hard to minimize falls, but [the administrators] are not providing a sufficient staff. So, it’s almost impossible to not have falls.” I witnessed countless instances of CNAs struggling or even failing to prevent falls, as in this situation with Betty:

> *Evie and I are sitting in the D-wing common area when Evie suddenly gasps. Betty has slid out of her wheelchair and is on the floor. Betty had been sitting behind a railing that was to assist residents with walking and balance, and she had hooked her feet under the bottom bar, grabbed the top bar, and pulled. She likely was trying to stand but instead she fell. It was so quick; it takes me a moment to process what happened. Evie calls one of the nurses, Karen, who comes in and sees Betty on the floor and says angrily, “Wow! Are you kidding me?” She then just turns and walks away. Evie is incredulous. “Does she expect me to pick her off the floor myself?” Evie and I stand helplessly with Betty, trying to comfort her. I look down the hall and let Evie know Tanisi, another CNA, is coming. Tanisi hands Evie her belt for transfers and they wrap it around Betty. Karen returns with the blood pressure and heart rate monitor and Brenda, the unit manager. It takes all four of them to lift Betty back into her wheelchair. Brenda shows a great deal of concern for Betty, asking her what happened and if she is okay. Betty says she is fine. Karen is still very angry. “Who was watching? Now I gotta make a freaking incident report!” Evie explains, “I was watching, but it happened so fast! I couldn’t get to her in time!” There were 21 residents being watched by one CNA. It seems almost unavoidable that some residents will fall some of the time under these conditions.*

Often, multiple old people with dementia were standing at once. The lack of engagement and activity in the dementia unit made them bored, restless, and agitated. Many wanted to walk, in order to just move or so that they could go to the bathroom, go to their rooms, or

look for the exit. When several residents labeled as fall risks were standing or walking at the same time, the CNAs would rush around the common area—at times, literally run—trying to ensure no one fell.

> *It is Umar's turn to supervise, so he comes into the common area to relieve Evie and take over. Evie comments, "My arm hurts [from trying to prevent a tall male resident from falling]." She sighs. "Okay, he's getting up [points to Harry, she's getting up, she's getting up, and she's getting up." She points to each of the residents who keep standing. "What? How am I supposed to handle four people at once?" Umar asks. Evie replies, "I don't know! I did it!" She shrugs despondently and walks to her wing.*

Even when multiple residents were standing at once, there was always only one CNA assigned to watch. Occasionally other CNAs would assist the CNA who was supervising but that typically only occurred if they happened to be in the common area for another reason, such as caring for one of their assigned residents or working on their documentation. Saavi, a CNA, once commented me during her supervision, when several residents were standing or walking at once, "This is not right, only one person cannot handle it!"

In many ways, watching/being watched was a site of temporal violence for the old women with dementia and the care workers. During my research, it was striking how much time I spent observing watching. It dominated much of the institutional routine, as the majority of the old women with dementia were always being watched unless they were in the dining room, doing an activity, or in their rooms to sleep. The old women with dementia were unable to have their needs met immediately and the CNAs would not allow them to stand or walk unless they had assistance. Therefore, they were forced to just sit, in their wheelchairs or chairs, for long periods of time, with little to no freedom to move or engage in an activity of their choice. For the CNAs, watching took time away from other important tasks, highlighted how understaffed Cedarwood Care Center was, and often placed them in impossible situations where they needed to be in multiple places at once to prevent falls. While they were watching, they were also being watched and faced consequences if a

resident fell. This surveillance gestures toward Foucault's (1995) concept of "panopticism," as the CNAs disciplined themselves into watching and rarely breaking the "rules" of watching (e.g., by taking a resident to the bathroom) out of fear they were being watched and would be punished. Although the old women with dementia and the care workers would at times resist the limitations placed on them through watching (e.g., by standing repeatedly or assisting a resident right when they needed it), watching ultimately served to survey and control their time in various ways.

E. **Conclusion: An Economy of Time**

The dominant temporalities in the dementia unit of Cedarwood Care Center—clock time, institutional time, and bureaucratic time—interwove in complex ways to influence the care relationships between the old women with dementia and the care workers. Cedarwood Care Center is not unique in this regard; nursing homes are increasingly regulated and organized around economies of scale, efficiency, cost-saving, and temporal parameters of care, such as ensuring residents are toileted every two hours and residents receive 3.8 hours of personal and nursing care per day (Rodriguez, 2014). Due to the dominant temporalities at work in the dementia unit, the old women with dementia had to navigate having their day strictly routinized, waiting for care, and experiencing constant surveillance and management. The care workers had to balance having a heavy workload, limited clock time, and a strict institutional routine with their desire to provide the best possible care to residents. Hence, care was largely organized through institutional and bureaucratic time, which created conditions of understaffing, low pay, high turnover, inflexible routines, needing to wait to provide or receive care, and surveillance.

Examined collectively, these conditions created a context in which time was a valuable yet scarce commodity. In her work on maximum security prisons, Rhodes (2004)

observed an “economy of attention,” which results in the construction of attention as a needed and useful good. As a result, people within prisons, including prisoners and prison guards, must seek, compete for, and provide attention at varying levels in different situations and contexts. Relatedly, I have argued that an “economy of time” is also at work in the dementia unit of Cedarwood Care Center. The care workers and the old women with dementia constantly struggled to acquire “enough time” to have their bodily, emotional, mental, financial, and social needs met. Instead, they were forced to find ways to survive and, as Guadalupe said, “do the best we can.” In the next chapter, I further explore how the dominant temporalities influenced the old women with dementia and care workers’ experiences of time and uncover how the care workers and old women with dementia disrupt and resist institutional and bureaucratic time by “making” time and “giving” time to one another.

V. GIFTS OF TIME: MAKING AND GIVING TIME IN THE DEMENTIA UNIT

What does it mean to “give” time to or “make” time for one another? How does giving and making time fit into feminist disability studies theories and politics of relationality and temporality? The more time I spent observing interactive moments between old women with dementia and care workers in the dementia unit of Cedarwood Care Center, the more I began to question the meaning and significance of giving and making time. Despite knowing and even using these idioms for years, I had truthfully never given it much thought. According to Merriam-Webster, giving time means to “use one’s time and effort to help others” and making time refers to “[causing] an amount of one’s time to be available to do something for or with someone” (“give of one’s time,” n.d.; “make time for (someone),” n.d.). Both of these idioms are based on the cultural assumption that time is valuable, and hence it is meaningful and important to give or make time to help, do something with, or do something for another person.

Furthermore, these idioms underscore that time is a central part of care. The physical, emotional, and social aspects of care that people provide to each other are temporally bound—they require time and also frequently involve repetition, duration, synchronizing, and routine. For instance, in their research on people with heart failure and their partners with chronic illness, Nimmon et al. (2018) discovered that the couples’ interdependence was closely related to time, as the participants reported that they were “taking it one day at a time,” synchronizing their activities and routines to take into account each partner’s changing needs and capacities, and adapting what they did for each other depending on which partner was having a “good” day or “bad” day. Such relationships highlight the interwoven nature of time, relationality, and care.

Feminist disability studies theories and politics offer a lens through which to analyze time, relationality, and care in the context of the dementia unit and other sites of care and

confinement (Ben-Moshe, 2020; Kafer, 2013; Price, 2015). Relationality refers to the ways people are connected interpersonally as well as structurally. One of the core ways that relationality is explored in feminist disability studies, and disability studies more broadly, is through the concept of interdependence, or the ways that people rely on each other to survive, and ideally, thrive. Patsavas (2014) highlighted the tradition within disability studies that "values interdependence over independence and seeks to situate experience within a framework of relationality" (p. 213). Certainly, a key part of interdependence is giving time to one another or making time for each other. This temporal element of interdependence is often illustrated through the praxis of crip time. Organizers delay the start of gatherings and events because not everyone may be able to get there "on time" due to environmental and social barriers or bodymind experiences such as needing more sleep and more time to get ready. Speakers seek to maintain a slow and steady place to allow time for live captioning and American Sign Language (ASL) interpretation. People pause during interactions, perhaps due to needing more time to think, wait for the captioner, or enter what they wish to express into their augmentative and alternative communication (AAC) devices. People give and take breaks, and breaks are longer and more flexible. There is a culture of flexibility and patience as groups work together toward collective access. In all of these examples, giving and making time is a key aspect of crip time.

Moreover, temporality is structurally embedded in interdependence. Price (2015) outlined three foundational points of knowledge in materialist feminist disability studies: (a) "identities are ever-shifting and contestatory;" (b) "the body matters (literally and figuratively);" and (c) "the body is constituted along specific lines of race, class, gender, and nation" (p. 271). Examining interdependence through these presuppositions reveals how temporality and care are interconnected and constructed interpersonally, culturally, and socially. Who is compelled or even forced to spend time together in care relationships? How

are old and disabled people and care workers bound to a schedule or routine of care? How are people racialized, gendered, classed, disabled, and aged in care relationships in ways that determine how their time is used or (de)valued? How is care quantified through time, and how is it determined how much time a person "needs" with personal care assistants, home health aides, CNAs, or nurses? How are personal care assistants and care workers compensated for their time? And to return to my earlier question, what does it mean to make or give time within this relational and structural context of care?

In the dementia unit of Cedarwood Care Center, the act of giving or making time seemed particularly significant. As I have argued, the dominant temporalities of the dementia unit created an economy of time, in which time was valuable yet scarce. Furthermore, neither the old women with dementia nor the care workers had much autonomy and choice regarding how they "spent" their time in this temporal economic context. Rather, their time was tightly controlled by the dominant temporalities at work in the dementia unit. Consequently, giving or making time unsettled the dominant temporalities in ways that allowed for shared moments of connection. In this chapter, I further unpack how the dominant temporalities in the dementia unit influenced how the care workers and old women with dementia perceived and experienced time[26] and how much control and autonomy they had over their time. I then explore the ways they disrupted or resisted the dominant temporalities by making time for and giving time to one another, thereby strengthening their interdependent care relationships.

[26] Throughout this chapter, I distinguish between perceiving and experiencing time. There are larger psychological and philosophical debates about the relationship between perception and experience of time that are beyond the scope of this chapter (see Le Poidevin, 2019). However, in the context of this project, perception of time refers to "the way of regarding, understanding, or interpreting [time]; a mental impression" (Taylor, 2019, para 3). Experience refers to "the process of living through an event or events" ("Experience," n.d.). In other words, perception of time refers to how time feels, how it is experienced through the senses, and how it is understood, whereas experiences of time refer to how time is spent and the activities or events that take place. Perception and experience of time are certainly interrelated, but there are also important distinctions that were significant in the context of the dementia unit.

A. The Care Dyad's Perceptions and Experiences of Time

The ways in which the old women with dementia and care workers perceived and experienced time were influenced by the dominant temporalities of the dementia unit. As previously discussed, the old women with dementia and care workers' time was regulated by the structures of care established by clock time, institutional time, and bureaucratic time, such as a strict daily routine and the need to wait to provide and receive care. In order to understand the significance of the care workers and old women with dementia making time for and giving time to one another, it is important to establish how the care dyad perceived and experienced time within the context of these dominant temporalities.

1. Care Workers' Perceptions and Experiences of Time

Due to understaffing and large resident to staff ratios, I often observed the care workers rushing from person to person and task to task. In many ways, I understood the care workers' time as defined by hustling. This fast-paced provision of care at times made the dementia unit feel chaotic. Even during their breaks, they were regularly hurrying to pick up or prepare food and quickly eat before their break ended. At times I would watch the CNAs literally run around trying to care for all the residents. This rushing was particularly common during "watching," when the care workers' primary care task was to prevent falls and ensure all residents remained safe.

> *There are three CNAs watching right now. Trishna is the CNA assigned to watch, but Angel and Jasmine have temporality suspended their usual care routines in order to help Trishna. Trishna needs help watching because a male resident, Herbert, is standing constantly and trying to walk. He is too tall and too strong for one or even two CNAs to prevent him from falling. He often will not listen to the CNAs and even occasionally threatens to strike them. In addition to Herbert, other residents who are labeled as fall risks are trying to stand and walk too, often at the same time that Herbert stands. Trishna is stressed because she is having trouble ensuring no residents fall, and Angel and Jasmine are stressed because they need to be caring for other residents, not helping Trishna prevent falls. Every time Herbert stands,*

> *chaos erupts. His wheelchair alarm sounds loudly.*[27] *The three CNAs rush to him, but he forces his way forward and comes very close to falling. Trishna, Angel, and Jasmine manage to help him step backward and sit back down but then realize that another male resident, Harry, had noticed all the CNAs were distracted and used the opportunity to try and walk off. They then run to Harry and help him sit back down. Harry is furious and begins yelling at them. "Fucking shit, you son of a bitch! God dammit! Why can't I leave!" Trishna tries to calm Harry but to no avail, and then Herbert stands yet again so the three CNAs have to run back to him. Herbert's wheelchair alarm and Harry's shouting and cussing are irritating the other residents in the group, some of whom are yelling "Shut up!" and "Turn that thing off!" Meanwhile, Betty has taken her shirt off, likely because she is hot. Trishna notices and cries out, "Oh my God!" and rushes over to Betty to help her put her shirt back on. This cycle repeats multiple times. It is constant pandemonium*.

Although this particular example was one of the more intense moments of chaos, it illustrates how rushed the care workers often were. During moments when I assisted them with direct care, there were times when I even found myself rushing and feeling rushed.

However, the care workers' perceptions of time did not necessarily align with their experiences of time at work. Due to the constant rushing, I expected the care workers to report that they also perceived time as passing quickly. Gladys generally agreed with this, noting, "Surprisingly, the days that are really calm, it is so slow. The time just lingers." Later, I questioned why Gladys had used the word "surprisingly," as her experience of time made sense to me. However, as I soon discovered, many other care workers reported that the busier and more stressed they were, the slower the time seemed to pass by.

> *Hailee: How do you experience time at work? Like does it seem to ever slow down, or speed up, or-*
> *Stella: It's always slow.*
> *Hailee: Why does it go slow?*
> *Stella: Well, it doesn't really go slow. It goes fast because you're always busy. It's not slow, it's busy-busy.*

[27] A wheelchair alarm is a pad that the wheelchair user sits on. When there is no weight on the pad, such as when the wheelchair user stands, the alarm sounds loudly until the person either sits back down or the alarm is turned off. A wheelchair alarm is technically considered a restraint and Cedarwood Care Center is a restraint free facility. However, Lulu (a nurse) informed me that the facility occasionally makes exceptions if a person is at a "very high risk" of falling and the Executive Director approves it. In Herbert's case, his wife requested the wheelchair alarm because she was so concerned about him possibly falling. The Executive Director approved it, based largely on Herbert's wife's request, but after a period of time it was removed, as it was deemed to be ineffective, too restrictive, and also upsetting to Herbert and other residents.

Hailee: So, you feel like it's nonstop?
Stella: It is nonstop but feels slow.

I realized Stella was reporting a discrepancy between how she perceived and experienced time—she was working non-stop, yet time felt slow as she was stressed and overwhelmed.

For Ciera, time also seemed to slow down when she was extremely busy. She identified her busiest days as the days the unit was short staffed or the days she did not have positive, trusting relationships with the other care workers. She stated:

> *"Well I know when we're short, it seems like longer. But if we have the right staff, and the right people here, it goes pretty quickly. Like, today is long, because Miss Evie, my [work] partner, is not here, who I work with. So, this whole week has been, very like, dreadful, until she comes back Monday. You know, we help each other so it speeds it up, we talk, you know, it just speeds up the day. If you don't like the people you work with, it drags, it does."*

For Ciera, being short staffed meant everyone had more to do. Moreover, her day was less stressful when Evie and the other permanent care workers in the dementia unit worked together as a team to help each other, which made time seem to pass more quickly. Generally, time is understood as passing by quickly or even "flying" when we are busy (Salleh, 2017), yet that was not the case for many of the care workers in the dementia unit. Perhaps there is a threshold and once we become *too* busy—as the care workers in the dementia often were—time no longer speeds up, but actually slows down and as Ciera said, feels "like it's never going to end."

2. **Residents' Perceptions and Experiences of Time**

Like the care workers, the old women with dementia were also at the mercy of clock time, institutional time, and bureaucratic time, albeit with different outcomes. Whereas I understood the care workers' time largely in terms of rushing and hustling, I understood the residents' time as characterized by lethargy and stagnation. When I would sit with the old women with dementia, as they were being watched by the CNAs, the passage of time often warped. As I wrote in my field notes one day, "Time sometimes

crawls on the unit. It passes so slowly. Thirty minutes feel like an hour." For the old women with dementia, there were long periods of silence and disengagement, when the only form of entertainment was the TV. Many just fell asleep either on one of the sofas or in their wheelchairs.

> *Nearly all the residents are sleeping. A few are watching the TV in silence. Eleanor turns to me and asks, "Are you sleepy dear?" "Yes, I'm a little tired," I respond. "Good for you! I am sleepy too!" Eleanor agrees. "Why don't you close your eyes Eleanor?" I ask. "Okay, my dear," Eleanor says and closes her eyes. She is asleep within minutes.*

Even though watching was often chaotic for the CNAs, if the majority of residents were sleeping, even the CNAs complained that time slowed down. When it was quiet and slow-moving, their exhaustion occasionally caught up to them.

> *Tashmiya is supervising. A cold is going around Cedarwood Care Center. Multiple residents and several CNAs, including Tashmiya, are sick. Tashmiya complains that on top of her cold, she is tired and her leg hurts from lifting and transferring. Most of the residents are sleeping, especially those who are not feeling well. It is so quiet. I notice Tashmiya is beginning to doze off in her chair. A dining services worker delivering the evening drinks and snacks notices and says, "Wake up!" loudly. Tashmiya jerks awake. "I'm not sleeping, I'm just resting my eyes!" she claims. Shortly thereafter, she calls Apple over and asks her to watch for a few minutes so she can go get some coffee from the dining room. "I need to sit down too, I'm so tired," Apple commiserates.*

In these moments, the care workers' experiences of time seemed to meld with the residents' experiences of time. Time was slow and monotonous, and the care dyad was exhausted—the care workers from difficult, debilitating work and the old women with dementia from the lack of stimulation and engagement.

In a study examining how people experienced the passage of time as they aged, Droit-Volet (2016) found that old people over the age of 75 living the in the community reported that time seemed to speed up as they aged. However, old people over the age of 75 living in nursing homes had a different experience. "Compared to their counterparts living at home, the oldest institutional residents retrospectively judged that time passed more

slowly now than before" (Droit-Volet, 2016, p. 77). Droit-Volet pointed out that a common stereotype was that time slowed down for old people because their cognition slowed down, but this research indicated it was the context of the institution that made time crawl or even grind to a halt.

Although the old women with dementia were at times resigned to the dull and repetitive nature of the dementia unit, they also regularly expressed frustration toward it.

> *Laurelle is sitting on the loveseat in the common area of D-wing. She is considered a high fall risk because she has a vision impairment and a medical condition that causes tremors and poor coordination, and consequently the CNAs are constantly asking her to stay seated. Laurelle stands suddenly and announces, "I want to stand!" She then sits back down of her own accord but bursts into tears. "Laurelle," Karina calls to her. "Laurelle, why are you acting like a baby?" Sylvia takes offense to this and retorts, "I'm not!" Karina laughs. "Thank you, Sylvia! Laurelle, you are not a baby, so stop acting like a baby and tell me what is wrong." Laurelle immediately stops crying. She stands back up. "I'm bored!" she complains. Karina smiles sympathetically and does not tell Laurelle to sit back down. "What do you want to do?" she asks. Laurelle sighs. "Nothing," she says. Discouraged, she sits back down.*
>
> *Fauna is sitting with her head in her hands. She lifts her head momentarily. "I've been sitting here so long doing nothing!" she cries out to no one in particular. "I don't know what to do with myself." She sighs heavily, puts her head back in her hands, and then sits in silence.*
>
> *Sophea is sitting in her wheelchair in the middle of the common area of B-wing. Her granddaughter usually sits with her, but she has left for lunch. When Harry walks by, she reaches out and smacks his hand. "You son of a bitch!" Harry yells. I intervene to deescalate the situation and lead Harry down the hall toward the lobby. But Sophea is not deterred. She backs up and hits Miles instead. "No!" Alyia calls out and runs over to move Miles out of reach. Sophea only speaks Khmer,[28] so Alyia simply repeats "no" multiple times and moves Sophea's wheelchair so she is sitting next to Alyia instead. However, Sophea manages to lean over, reach Eleanor, and hit her. "God dammit!" Eleanor cries out. Alyia tells Sophea no again and moves her so that she is even further from the other residents. Sophea's granddaughter returns and Alyia explains that she had to move Sophea because she was hitting other residents. Sophea's granddaughter asks her in Khmer why she was hitting people. She then laughs sheepishly and tells Alyia, "She says she hit other people because she is bored." Alyia lets out a little laugh and turns to Sophea. "Do you want to hit me too when you're bored?" Sophea laughs and shakes her head no.*

[28] Khmer is the official language of Cambodia.

The tedious and monotonous nature of the dementia unit was difficult for the old women with dementia. Families also sometimes expressed displeasure with how the old women with dementia were forced to spend their time.

> *Betty's daughter is visiting and asks me about my role on the unit. After I explain my research, she shares that the unit is "severely understaffed" and so there isn't enough interaction for the residents. She comments that her husband had dementia for 21 years and was in [another skilled nursing facility for many years, where they had way more activities, such as art, music, balloon tosses, drumming, etc. "But here? The residents don't do much—other than sit around."*

Lucille was perhaps the most determined advocate for all the residents, frequently asserting that they needed more stimulation, engagement, and connection.

> *The residents are all sitting. Some are sleeping, some are watching TV. Noticing the residents' apathy, Gladys asks Reyna, the Activity Director, "Are they doing a sing along today?" Reyna nods affirmatively but before she can say anything, Lucille interrupts, "More like a string along! What are these people doing all day? Just sitting here! Watching TV! It's not right!" Trying to redirect Lucille, Gladys tells her, "Here, Lucille, you can sit by Laurelle." "She's always sleeping!" Lucille points out, indignant. "Well, that's all right," Gladys tries to comfort her. "She must have been a busy lady and now she wants to rest." Lucille shakes her head but sits down. Reyna starts the sing along, which Lucille thoroughly enjoys. But as soon as the music ends, her anger at the lack of engagement returns. She asks bitterly, "So what do we do, just sit here now?!"*

Another time, Lucille was walking by me and noticed me writing in my field notes.

> *"What are you writing?" Lucille asks. I explain my research to her. "You're gonna get some wild stuff!" Lucille laughs. She pauses for a moment and then shares, "We don't have enough to do. We can't sit out here like this, night after night! Watching the news! It doesn't make sense for us! Not enough is done here!"*

Lucille and the other old women with dementia were frustrated by the monotony and repetition in the dementia unit. They would frequently advise the care workers that the residents needed more to do. Lucille was particularly adamant about making this point. Even at times when Lucille seemed perfectly content, if she noticed another old woman with dementia sleeping or appearing bored or disengaged, Lucille would use the opportunity to campaign for more interaction, activities, and ways for the old women with dementia to "pass the time."

The dominant temporalities of the dementia unit bent and distorted time for the care workers and old women with dementia—time was simultaneously fast yet slow, repetitive yet unpredictable, stagnant yet chaotic. Samuels (2017) discussed how one of the difficult aspects of crip time was the ways in which it functions as time travel, observing, “Disability and illness have the power to extract us from linear, progressive time…and cast us into a wormhole of backward and forward acceleration, jerky stops and starts, tedious intervals and abrupt endings” (para 5). Although Samuels was referring to disabled people’s frequent departures from normative life course stages,[29] her characterization of crip time as time travel is evocative of how time warped in the dementia unit. Although time was linear and progressive in the sense that the unit essentially functioned to provide the old women with dementia bodily care until their deaths, the actual lived experiences of providing and receiving care in a context of disablement, debilitation, and confinement created temporal shifts and ruptures, which the care workers and old women with dementia had to navigate as they made and gave time to one another.

B. **Time and (a Lack of) Self-Determination**

In addition to managing the ways their lived experiences of time converged and diverged in the dementia unit, the care workers and old women with dementia also had to contend with the lack of self-determination they had over their time. In what follows, I detail how care workers and the old women with dementia were forced to “spend” their time within the economy of time. Doing so provides additional context for the ways in which making time for and giving time to one another was a central aspect of the relational interdependence between the care workers and the old women with dementia.

[29] Old people with dementia are simultaneously aligned with normative life course stages (i.e., dominant narratives that dementia or senility is an inevitable part of old age) and divergent from them (i.e., competing dominant narratives that dementia is not a part of “healthy,” “normal,” or “successful” aging).

1. Care Workers' Control and Autonomy over Time

Notwithstanding the centrality of time to their work, the care workers had little control and autonomy over how their time was structured or how they occupied their time. Virtually every care task the CNAs and nurses did was temporally demarcated by Cedarwood Care Center or the State,[30] which created constraints on how the care workers elected to use their time. To use the example of bathing, the care workers had little to no choice regarding when residents were showered, except perhaps deciding when to give showers during their shift, although that was also restricted by mealtimes, activities, residents' appointments or family visits, and their own break schedule. During my observations of the evening shift, for instance, I only ever witnessed CNAs giving showers after dinner ended at 5:30 p.m., as there really were not any other appropriate times to give showers within the daily institutional routine. Thus, the CNAs and nurses had little self-determination regarding how to structure or spend their time. Unfortunately, it was hard for the old women with dementia or their relatives to understand just how little autonomy the CNAs had. At times, I noticed that CNAs would explain to residents and families that they "didn't have a choice" regarding making people wait for care or when they could complete certain care tasks. However, the residents and families would often become discouraged, frustrated, or even angry by such responses. Such emotions were due to their inability to receive the assistance they needed when the need arose, but also suggested they did not

[30] Toileting was to occur approximately every 2 hours for each resident. Dressing was to occur in the morning, after each resident woke, and in the evening, before each resident went to bed. Feeding was to occur during each of the three hour-long mealtimes: breakfast (7:00 a.m.-8:00 a.m.), lunch (11:30 a.m.-12:30 p.m.), and dinner (4:30 p.m.-5:30 p.m.). Transporting was to occur before and after each meal. Recording vital signs was to be done once per shift. Medications were to be distributed during mealtimes and/or prior to bed, depending on the prescribed dosage (e.g., every 4 hours, every 8 hours). Documentation was to be completed by the end of each shift. I describe these constraints in more detail in Chapter IV: Dominant Temporalities in the Dementia Unit.

fully comprehend the CNAs' lack of temporal control. Gladys disclosed how little choice she had regarding how she spent her time in an interview:

> *Gladys: So, in a nursing home…everyone is a fraction. So, all [the residents a CNA is assigned] add up to the whole. If I'm [a resident] in a nursing home and I don't really need your help being taken to the bathroom, I'm only 10% of [the whole]. So, even though I have 10 people, [the administration] look[s] at it as me having 8 people [because these two residents take less time to care for]. It's not looked at as, this is a whole person. But [the administration] say it's person-centered care, but [they] still view that person as a fraction. Because if I have to give half my time to this person and half my time to this person to make one whole, you're still looking at them as a fraction and not patient-centered care.*
> *Hailee: Right. So, they basically tell you, oh this person doesn't need as much help with the bathroom so spend less time on them?*
> *Gladys: Yeah. Pretty much.*
> *Hailee: Wow.*
> *Gladys: It's the dark side to it.*
> *Hailee: Yeah.*
> *Gladys: It is pretty dark to say but that's how it is.*
> *Hailee: Yeah. Well it seems like you don't really have a choice-*
> *Gladys: I don't. It's a resident's day to shower, you have to do that shower. You have two people who want to go to the bathroom, you have to figure out how to get both of them in the bathroom in this amount of time.*

Care work, in general, is highly variable and often unpredictable, but this is especially true when caring for multiple people, particularly people who are old and have dementia as well as other health conditions and impairments. Furthermore, the needs of the old women with dementia changed day-to-day as well as over time. And yet, the care workers had little agency over how to organize and spend their time in the dementia unit. Clock, institutional, and bureaucratic time created the structures of care that led to conditions of understaffing, low hourly pay, strict daily routines, persistent waiting and long wait times, and surveillance—and this context intensely limited the self-determination the care workers had over how to spend their time. Prior to further exploring making and giving time in the dementia unit, it is also essential to understanding how much control and autonomy the old women with dementia had regarding how they spent their time.

2. **Residents' Control and Autonomy over Time**

Like the care workers, the old women with dementia had little control and autonomy over how their time was structured or how their time was occupied. In her ethnography of a nursing home in Canada, Oldfield (2019) coined the term "resident's time" to describe:

> how nursing home residents would prefer to structure their time if they had the choice. This might include eating when they are hungry, going where they want to when they want to, going to the toilet when they feel the need to, and going to bed when they are sleepy. (p. 3)

Thus, resident's time does not refer to how people living in nursing homes actually spend their time, but how they would prefer to spend their time if their autonomy was preserved in the context of the institution. Despite these desires and preferences, Oldfield (2019) observed that resident's time was rarely acknowledged or honored in the nursing home due to the inflexibility of institutional time. As I discussed in the previous chapter, due to the intersections of institutional and bureaucratic time, the old women with dementia at Cedarwood Care Center were frequently forced to wait for their basic needs to be met, such as using the restroom or being transferred into bed. They also had no control over when meals were served or how long they had to eat. Activities were at a set time, and the small group of old women with dementia who were labeled as "high functioning" were occasionally given a choice about whether they wanted to participate or not, but the residents labeled "low functioning" were never given a choice.

This lack of choice and autonomy over time is not unique to Cedarwood Care Center, as these issues have been well documented in nursing homes throughout the United States (Sherwin & Winsby, 2011). In their study of nursing home residents in twenty-eight American nursing homes, Abbott et al. (2018) found that residents desired more

control over their time and indicated that they wanted to choose when to bathe, when to go to bed, when to get up in the morning, and when to eat. Such “simple” choices are often taken for granted by people who are not institutionalized. Boyle (2008) argued that the disability rights movement has fought for self-determination among disabled people, but that old disabled people have been largely left out of such organizing, particularly if they are institutionalized. She observed:

> Old age per se is frequently constructed as being equated with dependency, and dependency (related to impairment) is often assumed to be associated with vulnerability, passivity, and a loss of autonomy…Just as younger disabled people have been constructed as “dependent” on others, so too have older disabled people been constructed as “objects” of care, rather than being recognized as active agents or equal partners in caring relationships. (p. 302)

Such constructions aligned with Gladys’ assertion that not being able to provide more attentive, personalized care objectified the old women with dementia. Indeed, a core feature of person-centered care is autonomy (Fazio, 2018). However, the dominant temporalities of the dementia unit largely prevented the old women with dementia, like the care workers, from exercising much, if any, autonomy over their time.

C. **Giving and Making Time in the Dementia Unit**

Considering the ways in which the dominant temporalities of the dementia unit controlled how the care workers and old women with dementia perceived, experienced, and spent their time reveals why giving and making time was significant. Moreover, examining how the little self-determination the care dyad had within the economy of time in the dementia unit highlights how giving and making time unsettled the dominant temporalities to which they were subject. In this section, I further explore how the care workers and old

woman with dementia broadly understood the temporal aspects of care work, specifically analyzing how they made time for and gave time to one another in the dementia unit, which ultimately led to the development of stronger interdependent care relationships.

1. Care Workers' Understanding of the Temporal Aspects of Care Work

In their efforts to give time to and make time for the old women with dementia, the care workers had to navigate two competing temporal structures of care. The first structure is based on the dominant view, established by the government and adopted by the nursing home industry, that care can be quantified by requiring a minimum amount of time residents must receive assistance with their ADLs (e.g., 3.8 hours per day). The second structure is based on the care workers' personal ideologies and the desires of the old women with dementia for more personal, individualized care and strong care relationships. Although Cedarwood Care Center described the position of CNA as "providing residents with assistance with dressing, feeding, bathing, and other ADLs," with no reference to time, the CNAs understood that within the dominant structure of care, they needed to provide all their residents with assistance under specific time restrictions. In other words, they were keenly aware time was a fundamental part of their care work.

Returning to a prior example, the care task of bathing had multiple complex temporal dimensions. The CNAs had to ensure every resident was showered at least twice per week. The CNAs needed to give thorough showers to ensure the resident was clean but had to so as quickly as possible, so they did not fall behind on their other work. Moreover, the resident could not be showered just any day, but had to be showered on their assigned two days of the week, which were either Sunday/Wednesday, Monday/Thursday, or Tuesday/Friday. No showers were to occur on Saturday.[31] To keep to this schedule, the CNAs were expected to

[31] There were no showers on Saturday due to Shabbat (i.e., the Sabbath), as heating up water is prohibited due to the Torah's instruction not to build fires on the Sabbath.

shower at least two residents per shift. Thus, the CNAs understood that "bathing" was not simply a core care task for which they were responsible—instead, they discerned that they were responsible for bathing residents twice a week, on their assigned day, showering at least two residents per shift, and doing so in a timely manner.

The connection the care workers made between work and time due to the dominant temporal structures of care often became apparent when they defined care tasks according to not only how to do the task, but how long it "should" take.

> *Evie is frustrated because it is Ashanti's turn to watch at 11:00 a.m. but it's 11:02 a.m. and Ashanti has not come to relieve her. Herbert needs to use the bathroom, but Evie cannot take him until Ashanti is watching. Evie reports to Lulu, one of the nurses on duty, "Herbert needs help. Please page Ashanti." Lulu does but a few minutes later returns and says Ashanti is still shaving Bernard. Evie rolls her eyes. "So that's going to be her excuse. How long does it take to shave someone? It's 11:00, I need to go! It's past 11:00!" Reyna mocks someone shaving a face very slowly and chuckles. Ciera interjects, "Maybe she is still learning how. I used to not know how! Where's the teamwork?" "It's past 11:00 though, she should have been done by now, I need to go! I have to take this man to the bathroom; I can't be watching!" Evie snaps.*

The CNAs often became frustrated when another care worker was "taking too long," and they typically determined how long "too long" was based on their own temporal definitions of specific care tasks. Typically, their desire for other care workers to "hurry up" only surfaced when the amount of time the other care worker was taking directly influenced how much time they had with their residents. The CNAs would become even more irritated when the administration did not understand the temporal dimensions of a task they asked a CNA to complete. Gladys explained:

> *"So, you're taking care of someone. And [management] sees you're almost done. But then [they ask], "Oh yeah, by the way, can you go clip their nails real quick?" As if clipping their nails is like, 30 seconds? You know it don't take 30 seconds. This is what happens. They've been out of [the care worker] role so long, they forgot their steps to doing it. It's not just getting a nail clipper and clipping it off. And it's like, no, I can't just clip their nails. It takes 25 minutes! Because you have to soak their nails and then clean them and then clip them. And you have other people to take care of. It's like you're one person but they expect you to be 20. You can't do it."*

The care workers often expressed frustration that the administration held them to strict time requirements while simultaneously not understanding how long certain tasks required. Additionally, the care workers often experienced changing expectations about what their work entailed. For instance, toward the end of my fieldwork, Reyna, the Activity Director, announced that she was leaving Cedarwood Care Center. A week or so later, Karina shared that the administration had not announced any plans for activities for residents once Reyna left and she was outraged to hear that some administrators had suggested that the CNAs could take over activities. She stated:

> *That's not my job! I don't have training on how to do this, I don't have degrees. And I don't have the time! I have to watch, I have three people standing at once, what am I supposed to do? And when I'm not watching, I have too much to do! They just want to save money, it's terrible.*

Like Gladys and Karina, many of the care workers lamented how they were expected to do the work of more than one person, not only due to understaffing and high resident to staff ratios, but also due to unrealistic expectations about how quickly the care workers could provide care and how much time they had.

The temporal quantification of care was a constant source of struggle for the care workers and directly conflicted with the type of care many of the care workers wanted to provide. Ironically, even when the administration suggested the care workers provide more personalized care, the care workers explained that they could not do so without changes to the structure of the dementia unit and the dominant temporalities at work within it.

> *Ciera and Evie are talking in A-wing. Ciera shares that today the administration announced they are encouraging the CNAs to sit one-on-one with their residents. Evie looks at her in disbelief and shakes her head as if it were preposterous. Ciera agrees, "Can you believe that? Ain't nobody got time for that!"*

The care workers were intimately aware that the old women with dementia needed more engagement and connection and would benefit from more person-centered care, but it was incredibly difficult to care for the old women with dementia in this way. Despite this, many of

the care workers tried to make and give time to the old women with dementia as much as they could, although they had to do so while still meeting the quantitative temporal requirements of care and maintaining strong “time management.”

2. **Disciplining Care Workers through Time Management**

Despite the dominant care structures in place and the lack of self-determination many CNAs and nurses have, the nursing home industry treats CNAs and nurses as if they have complete control over their time. Instead of acknowledging the various ways in which care workers’ time is managed, the care workers are taught that they must manage their time. This skill in formal care work is referred to as “time management.” According to Nayak (2018):

> Time management is about how one manages [one’s] self. One cannot manage the time; one can only manage how [they] can use it. Organizing and prioritizing the patient care activities is of prime importance for providing quality care and to maintain the personal and professional balance…Time management is not only setting and achieving…goals but also accomplishing in minimum possible time. (p. 1997)

This definition of time management disregards the dominant temporalities at work in nursing homes. It also does not account for the hierarchal nature of long-term care facilities, which allows the owners and administrators to hold the vast majority of the power. Furthermore, exalting time management as a skill for care workers is reflective of neoliberal ideologies of individualism, self-reliance, personal responsibility, and productivity (Harvey, 2007). It urges care workers to act as their own disciplinary agents by managing their own time (Foucault, 1995). As a result, owners and administrators of nursing homes are able to maintain power with less application of force and care workers are discouraged from contesting the structures in place that limit and constrain their time.

The CNAs and nurses at Cedarwood Care Center were under extraordinary pressure from the administration and State to practice time management to ensure every resident had their care needs met. The administration encouraged the CNAs and nurses to continuously improve their time management, or if a CNA was struggling to complete all of the required care tasks for all of their assigned residents, the administration conveyed to the CNA that they needed to work on their time management or face consequences. Such admonishments emphasized that within Cedarwood Care Center and other long-term care facilities, care and time cannot be separated, but the onus of "managing time" is placed on the care workers without acknowledgement that they do not control the dominant temporalities or the resulting structures of care. Just as the CNAs were being watched while watching the old women with dementia, they were also being supervised and disciplined through time management.

3. **Balancing between Giving More Time and Practicing Time Management**

Although the CNAs and nurses in the dementia unit were aware that they lacked choice and control over how to manage their time, they still placed pressure on themselves to make time to provide more personalized, loving care to the old women with dementia. Even within the temporal confines of institutional care, the care workers were highly aware of the importance of the relational aspects of care. The care workers attempted to strike a balance between what they had to do for the residents and what they wanted to do for the residents. Unfortunately, as previously noted, this proved difficult, and at times, impossible. Gladys shared that the limitations on the care workers' time and the emphasis on time management directly affected her care relationships with the residents. She explained that she would have to "pull away" and remember "it's a job":

> *Hailee: What do you mean by [you have to pull away] because you forget it's a job?*
> *Gladys: Because you're trying to go out of your way [to do special things for the residents]. And then going out your way ends up having you fall behind on your*

> *work. Now that sounds like [treating the residents] like objects, right? But no, they're not. So, if I have to give, say it's your shower day, I'll give you a shower. And I notice you're enjoying your shower, you want to take a longer shower, right? I can't do that. Or, if I do keep [giving you a shower], when it's time for me to go push my people to the dining room, or to give the next person a shower, or this person have to use the bathroom, and they don't get my attention or my help. And then that falls on me for not having time management. And that's when I feel like people become objects more than people, with work.*

Thus, Gladys felt she had to "pull away" when she found herself giving too much time to individual residents. When I asked Gladys to go into more detail about why she pulled away, she revealed it was to protect herself emotionally because it was difficult for her to not to give additional time to the old women with dementia so they could receive more individualized, humanizing care. Apple and Stella both shared what I would characterize as "fantasies" of ways they would care for the residents if they did not experience time constraints or pressure to practice time management. These fantasies included sitting and talking with the residents, reading with or to them, taking them outside on the patio to enjoy sunshine and fresh air, taking them on walks around the building or on the patio, helping them exercise, and playing music for them. Such fantasies may have been their way of coping with the reality they could not give as much time as they wanted to every old woman with dementia.

Gladys also implied that finding a balance between wanting to give more time to the old women with dementia and practicing time management was a constant struggle due to job security, stating:

> *Because if someone's to come approach me and tell me, oh Gladys, you took too long giving Sally a shower. If I didn't give her the shower, then I didn't do my job. But [it's the same thing] if I took too long giving her a shower. So then, you get torn between [what you want to do for the resident] and time management. But if you don't use time management, eventually management will come talk to you.*

Hence, giving or taking "too much time" to care for the residents possibly led to consequences, ranging from a warning, write-up, or even dismissal—an outcome Gladys, a

mother of two small children and a caregiver to many family members and neighbors—could not risk. Few of the CNAs or nurses could, as many were multiply marginalized women who were financially supporting children, parents, grandparents, cousins, and neighbors. Quite a few of the CNAs who were immigrants, such as Alyia and Ashanti, also reported sending money back to their family members who still lived in their countries of origin. The care workers' marginalization and exploitation, which was directly related to their need to survive and support their families, resulted in them frequently conforming to the expectations of "time management," despite how difficult it was for them to do so.

Within this context, the care workers were encouraged to be their own disciplinary agents through practices of time management, yet had little autonomy and control over how they spent their time. Despite this, the care workers tried to push back against time management. Stella shared that when she felt her residents really needed her, she resisted the pressures of time management by making time for them:

> *Hailee: What do you do when you see that [one of the old women with dementia is in distress]? What do you try to do to assist them?*
> *Stella: I spend time with them. I know I have 13 other people, but in a case like that, I feel that's how I deal with my residents. To me, that's an emergency. So, I spend more time with them. I'll get them comfortable, you know, and I just spend more time with them.*
> *Hailee: So, you give them one-on-one attention?*
> *Stella: Give them the one-on-one even though I don't have the time, but I make the time. Being a one-to-one person, if I see one of my residents [is] upset or something like that, I try to accommodate them—no matter how long it takes.*

Gladys expressed how making time to give residents time was an important way she reclaimed power in the dementia unit:

> *"I may not affect a million people every day, but I made a difference in twelve people's lives today. I made sure they were clean and ate and were happy for eight hours. And that takes power. You have the power to affect people. I know for eight hours or the amount of time I had them, [the residents I am assigned] had a good day compared to having a bad day the entire time they were awake. Because they were…given time to do something they liked or wanted to do [instead of being] looked at as an object that you had to deal with that day."*

Hence, even as they were cautioned against giving “too much time” and instructed to manage their time, the care workers still found ways to make time for and give time to the old women with dementia.

4. The Temporal Aspects of Care for the Old Women with Dementia

The old women with dementia at Cedarwood Care Center, like the care workers, understood care as interconnected with time. However, it was not temporally bound in the way the State defined it, i.e., requiring each resident to receive a minimum of 3.8 hours of nursing and personal care a day. As the recipients of care, the old women with dementia also were not focused on the “amount of time” required to complete specific care tasks related to ADLs. Rather, the old women with dementia felt cared for when the care workers could spend time with them, give them individualized attention, provide them with companionship, and meet their social and emotional needs in addition to their physical needs—in other words, make and give time to them in ways that resisted the structures of institutional care and affirmed their personhood (Kitwood, 1997).

Alice was receiving the amount of care required by the State and did indicate she felt the assistance she was receiving with her ADLs such as dressing, bathing, and transferring in and out of bed was perfectly acceptable. However, for Alice, a central part of care was about having a relationship, which required time to develop and sustain. When I asked Alice about her relationships with the care workers, she responded, “I would say they're efficient. They do their job. [They are] busy.” I was struck that rather than describing her connections to the care workers, Alice focused on their job performance, efficiency, and how much they had to do. As Alice continued talking, I learned that she felt the care workers were too busy meeting everyone’s basic needs to be a friend to her, which is what she was really craving.

Alice was a white Jewish woman in her 80s and one of the residents in the dementia unit at Cedarwood Care Center who had no living family, and thus had been declared a

ward of the State. Alice had been married and had a son, but her son had passed away from heart failure when he was just 20 years old—an immense loss Alice continued to mourn. Shortly after his death, her husband left her. As Alice aged and she became more disabled, she was increasingly segregated. Prior to her institutionalization, she had been lonely, so she had actually looked forward to moving to Cedarwood Care Center, but she struggled to find her place in the dementia unit. She was quiet and, at times, shy, which mattered greatly in a context in which the most outgoing and extroverted residents often received more attention.

Alice was labeled as one of the “high-functioning” residents and got along well with Fauna and Lucille, two other residents who had also been labeled high-functioning, but she understood herself, Fauna, and Lucille as “normal” and many of the other old women with dementia as “mentally ill.” Multiple times during our interview, Alice shared that she knew all the other women were “mentally ill” because during musical activities, only Fauna, Lucille, and she would sing along to the songs. Unfortunately, believing that she was only “sane” person in a unit full of “mentally sick” people made Alice very anxious and even more quiet and reserved. She spent much of her time reading and rarely talked to any of the women aside from Fauna and Lucille. She did participate enthusiastically in almost every activity, but there were only a few per day. Alice viewed the care workers as people she could possibly talk to and connect with, but felt they were often unavailable or too rushed. She shared:

> *I don’t have relationships with the staff. No, I don’t think anyone does. It's not [the care workers’] fault. They're very busy. They are very busy and they're efficient. But I can't really talk to anybody…I need help, I need a friend. And that’s hard to get.*

Alice wanted to have closer relationships with the care workers but did not even see it as a possibility because they did not have enough time.

Fauna also defined care in temporal terms but, unlike Alice, being cared for meant having a daily routine that ensured Fauna did not have to stress or worry about anything. Fauna was a 96-year-old white Jewish woman. She had married when she was young and had children, but that marriage did not work out and she and her first husband divorced. She remarried, and her new husband had also been previously married and had children. Fauna always emphasized that she had wonderful children and her stepchildren were also always so kind and accepting of her. She felt very lucky in that regard. Fauna told me that she had decided to move into Cedarwood Care Center after her doctor found out she was 92 years old and still driving and told her she couldn't drive anymore. However, Brenda, the head nurse, told me her children had decided that Fauna needed to be placed in a nursing after she had broken her arm and could not live independently anymore.

Perhaps because Fauna had been struggling to live alone, she placed a great deal of importance in the care workers taking care of making her bed, placing her dirty clothes in a hamper, sending her clothes to the laundry to be cleaned, and hanging the clean laundry back in her closet. She explained:

> *I would get ready for bed at night…[the bed] was made already! And I would leave my clothes that I took off on the bench, you know there. And they next day they would pick them up! And the next day somebody would put them back! They would get my clothes that they washed and bring it back and hang it in the closet and everything was, it was perfect…And the fact that they took the laundry for me, I didn't have to worry about where am I going to go for my laundry or anything. And my closet was always nice. I have nothing to complain about!*

Later in our conversation, Fauna similarly said:

> *Well, at night, if I was going to go get ready for bed, [the care workers] were there. They would help me get undressed. And they would take my clothes and put them ready to take them to the laundry. So, they will do that, you know, get my clothes out, my night clothes, and I would go to bed…but I know the girl in the morning will come and help me get dressed. Not a single bad thing!*

Fauna repeated this specific example of having her bed made, her dirty clothes picked up, and her laundry done nearly every time I asked her to talk about the care she was receiving

or to talk about how the staff cared for her. Being able to count on these needs being met every day, and not having to worry about tasks she likely did stress about as an old woman living alone, clearly meant a lot to her.

Furthermore, distinct from Alice's experiences, Fauna felt the care workers did make time to connect with her and build a relationship with her even though they were busy.

> *Fauna: The girls who work here, they're nice.*
> *Hailee: How are [the care workers] nice to you?*
> *Fauna: They're nice.*
> *Hailee: That's good!*
> *Fauna: They just talk nice, you know, and we would, sometimes we will laugh a little bit. A lot of times, they would look at the pictures [of my family] and stuff like that and they ask me who is what, and the other thing. And they would get a kick out of it! And they would say, well this one looks so fat. (Laughs.) And the best way that, that picture was my—it was one of my first husband with the children you know. (Laughs.) Stuff like that.*

Talking and laughing with the care workers was important to Fauna, and she liked that they showed an interest in her family and would often bring her family up. Having this personal connection in addition to following a care routine that made her feel secure was important to Fauna.

Lucille also felt the care workers made time for her, especially when she needed it. When I asked her about the care she received, Lucille told me she did not need help with anything like showering or going to the bathroom, but she did need the care workers to pay attention to her and comfort her when she was upset.

> *Hailee: What's good about [the care workers]?*
> *Lucille: They're very comforting, if you have a problem on your mind, they'd come up to you and they say, "Well, what's bothering you? Let me hear about it." That's very good.*
> *Hailee: So, they listen to you?*
> *Lucille: Sure. I think that the staff is wonderful. They are very good feeling people.*
> *Hailee: How do they show you that they care about you?*
> *Lucile: By paying attention to me. When I need attention. […] I mean, I feel very much at home here, that's a good way to put it…It's a homey feeling.*
> *Hailee: So, you feel like it's like home, people care about you?*
> *Lucile: That's right.*
> *Hailee: That's wonderful.*

> *Lucile: Yeah. It's a good feeling, and that's how it is. I feel that way. I feel that my grades are good and that's because my teachers are good here too.*[32] *And that counts a great deal.*
> *Hailee: That's good you're getting good grades, I'm not surprised! […] Do you think the women that work here have an easy job or hard job?*
> *Lucile: They have a comforting job, they have a job that is a comfort to you. In other words, if I have something on my mind, I feel like I can talk to one of them, like I am talking to you now. That I have that same, that…I am still involved with that. That's just what I am thinking. I feel comfortable here, that's a good word for it.*
> *Hailee: What do the women that work here help you with? Do they help you shower, get dressed—*
> *Lucille: No, no, I've never needed that…I think I am okay with just being here.*
> *Hailee: So, it's more about them listening to you, respecting you?*
> *Lucile: They do, they do.*
> *Hailee: That's wonderful.*
> *Lucile: Yes, they do. And they have that reputation everywhere, I want you to know that. That made me want to print, to pick this school. That was one of the qualifications on my mind.*

Lucille was an 88-year-old white Jewish woman and was one of the more "independent" residents in the dementia unit, especially since she was not labeled as a fall risk. However, she did receive some help with a few ADLs, but that assistance was not present in her mind when I asked her about the ways in which she received care. Lucille did not understand care as assistance with bodily tasks, but rather conceptualized care as the care workers taking the time to pay attention, listen to what she was feeling or thinking, and comfort her.

Ramona and Tala also appreciated when the care workers would take the time to check on them, ensure they had everything they needed, and make them feel important. Both women compared these forms of care to the care one receives from family. In fact, Ramona and Tala compared the care workers to having mothers. Ramona was an 80-year-old Black woman. Ramona had been married but her husband was no longer alive. They had six children, all of whom came to visit Ramona regularly and were very involved in

[32] During our interview, Lucille went back and forth between talking about the care workers in the context of Cedarwood Care Center and referencing them as though they were teachers in the boarding school she had decided to attend. I did not "correct" or "reorient" Lucille but rather affirmed whichever reality she was in, a practice that I discuss in more detail in the next chapter on dementia time.

Ramona's life, so it was not surprising to me when Ramona began talking about care in the context of motherhood.

> *Hailee: How do [the care workers] take care of you?*
> *Ramona: Those ladies is doing this much. She's trying. And so, you know. It was real good.*
> *Hailee: How was it real good?*
> *Ramona: And the babies is—are with their mama.*
> *Hailee: Yeah, the babies are with their mama?*
> *Ramona: Mmhmm.*
> *Hailee: And are they taking care of the babies?*
> *Ramona: Oh yes! Mmhmm.*
> *Hailee: Good. And you feel like they take good care of you? Just like how you took care of your kids.*
> *Ramona: Yes!*

Ramona's comment about the care workers doing "this much" and "trying" suggested she understood them as busy but making an effort to care for them as she cared for her children. Tala also talked about how the care workers took the time to make sure she was eating and doing well and talking to her about how she felt. Tala was an 87-year-old Filipina woman who had immigrated to the United States as a young adult. She had a daughter who was a nurse and came to visit her as often as she could. Like Ramona, Tala compared the care she received from the care workers to motherhood and being cared for by family.

> *Hailee: How do you feel about living here?*
> *Tala: Nice.*
> *Hailee: What do you like about it? What makes it nice?*
> *Tala: It's like a home.*
> *Hailee: It's like a home, that's good. In what ways is it like a home?*
> *Tala: When you are sick, somebody would come and visit you. [They] care and if you are—if it is time to eat and I am still here, somebody would come and tell me, it's time to eat.*
> *Hailee: That's nice. What else do they do to show you that they care?*
> *Tala: They really like a home—like a mother. Like you have a mother here.*
> *Hailee: Yeah, that's really nice. And how do you feel about how they care for you?*
> *Tala: Very good.*
> *Hailee: What's good about it?*
> *Tala: Living here is like living in your own home…like you are take cared of (sic) by your family.*
> *Hailee: So just how your family would take care of you. What kinds of things do they help you with?*

> *Tala: Somebody would come and see how you feel. You feel so important to them. Somebody would come and say, how do you feel? Then if I don't go to the kitchen, they come to get me so I go to the dining room and eat.*
> *Hailee: Yeah, so making sure you're eating.*
> *Tala: Yes, making sure I eat.*
> *Hailee: So it feels like home. Do you feel like you have people to talk to?*
> *Tala: Yeah.*
> *Hailee: What do you talk to the care workers about?*
> *Tala: How you feel. And the food.*

According to Ramona and Tala, the care workers demonstrated that they cared for them by making them feel important, like their family members. It was significant to them that the care workers made time in their schedules to stop and check on them, talk to them about their feelings, and make sure they were eating, had enough food, and liked the food. Clearly, this reminded them of the care they gave and received within their own families.

Another important temporal aspect of care for the old women with dementia was that interdependent care relationships could only be developed *over time*. In other words, the passage of time was a primary factor in the development of relationships between the old women with dementia and the care workers. This criterion is important for all relationships, but it was particularly important for the old women with dementia who were non-verbal, who experienced confusion, disorientation, and distress, and who spoke primarily or exclusively in languages other than English. Gladys explained how the care workers developed intimate knowledge[33] of the old women with dementia for whom they cared:

> *Hailee: I have noticed a lot of the CNAs and nurses do things that they just seem to know are the preferences the residents have. How does that work?*
> *Gladys: It's just something you learn. This one lady who, when you give her the food, if you forget to put a bib on, she'll be like "Ahh, ahh, ahh," and she'll hit her chest [so we know] to put it on. Or, if she wants something to drink, she'll just grab a straw and*

[33] Disability justice activist Mia Mingus (2011) forwarded the phrase "access intimacy" to explain the "elusive, hard to describe feeling when someone else 'gets' your access needs" (para 4). Although the care relationships between the old women with dementia and care workers were certainly intimate and the care workers did develop a deep understanding of the residents for whom they cared, I am hesitant to refer to this aspect of their relationship as access intimacy, as their intimacy is occurring within an institution, which is a site of forced intimacy for disabled people, including old people with dementia (see Mingus, 2017).

> *wiggle it. Or Liza yells, "Mama, mama," when she wants to go to bed after lunch. Or, if she doesn't want to go to bed, she will do this…echoing noise that means she wants to go to the bathroom. But I think it's just something you learn. Because they do it so frequently. You're like, oh, this is what she wants when she does this. Or Bernice, starts to stand up non-stop when she has to use the bathroom. Then you take her to the bathroom and all of a sudden, she's calm. You just learn over time.*

The care workers made an effort to spend enough time with the residents to learn more about them, their preferences, and how they communicated, which facilitated the development of trust. As a result, the care workers often were able to care for old women with dementia whom others might characterize as "impossible" to care for due to their chronic and progressive disabilities.

For instance, some of the old women with dementia, particularly those who did not communicate verbally, seemed to express a connection between time and care in embodied ways that the care workers understood and valued.

> *Often, when a care worker, especially Karina, passes by Nadine, Nadine stretches her arm out as far as she can and opens her hand wide. Nadine does not communicate verbally but communicates a great deal with her body language. Her outstretched hand signifies her desire for human contact. Unless they are really rushing, the care workers will smile and take her hand. Nadine almost never wants to let go. The care workers will stay and hold her hand and smile and talk to her. Some spare only about thirty seconds, others spare a few minutes, but the care workers always must eventually walk away. Nadine and the care workers smile at each other as they part ways.*

Other old women with dementia who did not communicate verbally, did not speak English, or had aphasia also would seek the care workers out for physical contact and affection. They would hold the care workers' hands or rub the care workers' backs. Often when the care workers needed to walk away, the old women with dementia would express in some way they did not want them to go—they wanted more time with them.

Although the old women with dementia perceived the care they received differently and focused on different aspects of care, all the forms of care that they highlighted had a temporal element and it meant a great deal when the care workers spent time with them.

The old women with dementia were not focused on having their physical needs met through assistance with ADLs. Instead, they focused on the care workers making the time to check on them, talk to them about how they felt, comfort them if they were distressed, ensure they had enough food to eat, and show them affection. This type of care led some of the women to compare the care workers to family and understand Cedarwood Care Center as more of a home-like environment.

5. **Partners in Care: Old Women with Dementia Giving Time**

Although care, particularly in institutions, is typically understood as one sided, the old women with dementia also tried to make time for and give time to the care workers. Although they did not have the same pressures on their time and were likely unaware of the specific temporal restrictions defined by the State and administration of Cedarwood Care Center, many residents were aware of how strained and pressed for time the care workers were trying to complete their work. Given this, the old women with dementia made time to acknowledge how busy the care workers were and thank them, even for everyday tasks the care workers might be "expected" to do.

> *Meera is rushing around the common area, trying to ensure that her assigned residents are able to use the restroom before dinner, because once dinner begins, she only has an hour to assist all the residents who need help eating and so toileting in the middle of mealtimes is very hard. In the middle of her rushing, Betty stops her quickly just to tell her, "You are busy, busy!" Meera laughs, grabs Betty's hand and squeezes it.*
>
> *Eleanor is really enjoying her juice at dinner and finishes it quickly. Serena notices and brings her more juice. "Oh!" Eleanor is pleasantly surprised. "Oh, thank you my dear!" Eleanor then turns to another old woman with dementia at her table, Marlene. "She did that for me!" she tells her. "I appreciate that!" Marlene shares in Eleanor's happiness over this simple gesture of kindness. "Yeah she did! There you go, kiddo!" Serena smiles.*
>
> *As I am walking from the common area toward the lobby, Alice suddenly starts screaming. "My book! My book!" she shrieks. "Someone stole my book! Someone stole my book!" She is looking all around her wheelchair in a panic. Karina walks quickly over. "It's okay! It's okay! You set your book next to you, in your chair! See,*

> *it's right here!" Alice immediately calms down. "Oh, thank you. Thank you so much. Thank you!" Karina nods, says, "Of course!" and hands Alice the book.*
>
> *Evie walks past the table where Sylvia and Ramona and I are sitting at dinner. She looks exhausted and overwhelmed. She sighs heavily and says, "Oh my God!" Ramona commented empathetically, "That woman must be tired," clearly aware Evie was working hard. Evie overhears, looks over at Ramona, and gives her a small smile of appreciation.*
>
> *Laurelle's bun is falling out. Laurelle used to be a hair stylist and she wore her hair up in a bun every day, so it is often distressing to her when this happens. Anastasia, another resident, tries to help by smoothing her loose hairs so they are out of her face. Stella is walking by and notices. She stops, thanks Anastasia, and tells her she will fix Laurelle's hair. She grabs a brush and tells Laurelle, "I am going to fix your bun!" "Okay!" Laurelle says, pleased. Stella brushes Laurelle's hair out and then carefully pulls it up into a bun. Laurelle feels the bun. "That's good!" she replies. "Thank you!" "Spasibo!"[34] Anastasia affirms. Stella smiles. "You are welcome!"*

There are countless more examples of the old women with dementia taking the time to acknowledge how hard the care workers were working and share their gratitude.

The care workers were also grateful to the residents for taking the time to show appreciation, especially in a line of work where they often felt invisible and undervalued. Ciera talked about how important this appreciation was to the care workers:

> *Ciera: Nobody appreciates you here [at Cedarwood Care Center]. But the residents.*
> *Hailee: How do the residents show appreciation?*
> *Ciera: Well, they always smiling! Or some can verbally say thank you. Bernard says thank you all the time, Fauna will. Vladimir and his wife say thank you in Russian. Or you know, they will just touch your hand. Give you a hug. Give me a kiss, kiss my hand.*
> *Hailee: [We have talked about how] this is a stressful job, it's hard work. What makes your job feel "worth it"?*
> *Ciera: Providing care for the residents. Making the residents feel good. I try to treat my residents like my family. Seriously. And I think just them, them appreciatin' it. Appreciating you.*

Another way the old women with dementia tried to give time to the care workers is by telling them they did not need to assist them with certain tasks.

> *Marlene begins crying and says she has to go to the bathroom. Ashanti asks me to watch so she can take her. Ashanti takes Marlene into an empty bathroom, but then*

[34] Spasibo (спасибо) means thank you in Russian. This was translated for me by Karina, a Russian speaking CNA.

Marlene begins screaming. I can hear Ashanti try to comfort her, but she keeps screaming. They emerge. Marlene has tears streaming down her face. Ashanti tries to comfort her. She is very focused on trying to figure out what Marlene is experiencing. "Why are you crying?" she asks. "Are you in pain?" Marlene replies, "I was in pain but not anymore." Ashanti tries to confirm this. "Your pain is gone?" "No, I don't have a gun!" Marlene responds. "Where are you hurting?" Ashanti tries again, using different words. Marlene doesn't respond but rubs her stomach. "Here?" Ashanti asks. She points to Marlene's stomach. "I am going to go get the nurse." "No, I'm fine!" Marlene tries to insist. "I'm fine, I'm fine! Thanks kiddo." Ashanti pats Marlene's hand in appreciation but leaves to report Marlene's stomach pain to the nurse anyway.

Isabelle wears compression socks and wraps on her feet to help with swelling. Brenda comes by and notices the socks are a bit dirty and the wraps are coming loose so she returns with new socks and wraps. As she begins changing them, Isabelle tells her, "Oh thank you, you don't have to do that!" "It's okay," Brenda reassures her. "I am here to help you, we are all here to help you!"

Although the care workers always insisted on helping, they understood that the old women with dementia were trying to make their workload lighter and were thankful for their efforts. The old women with dementia would also give time to the care workers by trying to assist them with their jobs in other ways.

At dinner, Bernice's assigned CNA, Guadalupe, suddenly shrieks, "Bernice! Where is Bernice?!" Bernice's empty wheelchair is at her table, but Bernice is nowhere in sight. "Oh my God, where is she?" Guadalupe exclaims. Everyone begins looking around. "There she is!" one of the other resident's private caregiver points. Bernice is standing at one of the back tables, stacking dishes and cleaning the table. Guadalupe laughs a little, clearly relieved and a little touched by the gesture.

Laurelle has been standing repeatedly for over half an hour and every time Ciera has to ask her to sit back down. Ciera is getting increasingly frustrated. The next time Laurelle stands, Marlene intervenes, calling out, "Sit down and be nice!" Laurelle ignores her at first. "No, no, no, no sit down!" Marlene orders. Ciera says, "I like how you take control Ms. Marlene." "You have to!" Marlene responds. "And sometimes you have to get a little nasty!" Ciera laughs. Laurelle stands again and Marlene does not hesitate. "Hey! Sit down! SIT DOWN! Thank you!" "Tell Harry to sit down next, Marlene," Ciera jokes. "Oh," Marlene waves her hand dismissively. "He never listens!" Ciera and Marlene laugh.

Herbert keeps standing and then takes his shirt off. Tashmiya tries to help him cautiously. "I can help you put that back on." Herbert tries to strike her, so she backs off. "I am not going to fight you; I only want to help you," she explains. After a few moments, she tries to help Herbert again. This time he allows her to put his shirt on but afterward ties to hit her again. "You cannot hit me! You cannot!" Tashmiya says firmly. At this point, Fauna gets involved. "Leave her alone! Stop it!" "Why are you

> *sticking your nose in this?" Herbert asks Fauna. "Because you are not being nice! I would hope a man like you would be nice and quiet and let these women care for you!"*

In these moments, the old women with dementia approached care as collective and communal, rather than as a hierarchal, transactional relationship in which they were the receivers or consumers of care and the care workers were the providers of care. Instead, by giving and making time to each other, the old women with dementia and the care workers became partners in care. Although they were not equal partners due to their differing social locations and distinct experiences of marginalization and exploitation, the care dyad challenged the dominant temporalities of the dementia unit through small gifts of time. In this regard, making time and giving time became sites of resistance and survival.

D. **Conclusion: Gifts of Time**

Both the care workers and the old women with dementia understood the importance of spending time together. However, given the economy of time and the restrictions created by clock time, institutional time, and bureaucratic time in the dementia unit, the care dyad had to make time for and give time to one another. Whereas the economy of time sought to dictate how the old women with dementia and care workers “spent” their time, giving and making time represented an “investment” of time. In other words, through giving and making time, old women with dementia and care workers invested in their relationships—an aspect of institutional care that is uncompensated, overlooked, and undervalued. The scarcity of time established by the dominant temporalities in the dementia unit constructed even small gifts of time as extraordinarily valuable. In this chapter, I have further examined how the dominant temporalities influenced the ways in which the care dyad experienced time, how much (or how little) self-determination they had over how they spent their time, how they understood care and temporality as intertwined, and what it meant to make and give time to

each other in this context. Interspersed throughout, there have been numerous examples of how the care workers and old women with dementia made and gave time as part of their interdependent care relationships, but I conclude this chapter with a few additional moments that represent "gifts" of time. Understanding the economy of time at work in the dementia unit transformed kind, yet seemingly mundane and minor gestures, into meaningful moments of care and interdependence.

> *I am sitting in common area of C-wing with the residents, next to Laurelle on the love seat. The news is on, but no one really watches. Many of the residents are asleep. Evie is watching the residents, and Karina, who is assigned to care for the residents who live in C-wing, hustles about the room, toileting residents, changing any clothing soiled with food, urine, or excrement, and ensuring the residents have fresh towels and linens in their rooms. Laurelle suddenly announces, "I am thirsty!" Since Evie must watch and cannot leave the residents, I offer to go to the kitchen and fetch Laurelle a glass of water. I bring it back and Laurelle takes a sip but hands it back to me. She says, "That's not good! I want something good to drink!" Evie offers Laurelle a milkshake from the daily snack tray, and Laurelle drinks it but then asks for more. Evie tells her each resident only gets one, there is no more. "I want something good to drink!" Laurelle repeats. Suddenly, Karina, Laurelle's CNA, appears. I had not seen her in the common area for a few minutes, so I had assumed she was with another resident in their room. I notice Karina has gone to the kitchen and picked up Laurelle's personal cup that has a lid to prevent spills and a straw. "I have something good to drink!" she announces triumphantly, handing the cup to Laurelle. Laurelle takes a sip and her face lights up. Karina smiles and winks at me, whispering that it is carbonated water. "Where did you get this?" Laurelle asks, surprised. "From my cousin?" "From your fridge! [Your son] brought it for you!" "Ah, yes!" Laurelle replies gleefully, taking another long drink. Karina shares that Laurelle doesn't care for tap water but loves carbonated water.*
>
> *It's dinner time. Sylvia notices Trishna hurrying by with a cart full of plates on her way to serve residents at one of the tables in the back of the dining room. "You are so pretty!" Sylvia calls out. Trishna serves the residents and then quickly returns to Sylvia's table. "Thank you so much Sylvia! You are so pretty too!" She strokes Sylvia's face lovingly. "Oh thank you!" Sandy smiles. "You are welcome!" Trishna responds, taking Sylvia's hand in hers. Sylvia pats her hand. A few minutes later Ashanti serves Sylvia her food. "Thank you, sweetheart!" Sylvia tells her. "Oh, Sylvia, I love you," Ashanti responds. "Give me a hug!" Ashanti and Sylvia hug, look into each other's eyes, and smile.*

If a casual observer or infrequent visitor to the dementia unit had witnessed these interactions, they may have interpreted it as Karina simply "being nice" or even "just doing her job," and Sylvia being "a sweet old lady." However, after immersing myself in the

dominant temporalities of the dementia unit, alongside the care workers and old women with dementia, I understood the significance of these gifts of time.

It is important to acknowledge that the care relationships between the care workers and old women with dementia were not perfect or ideal. As with all relationships, they were complicated and at times, outright messy. These complexities were amplified by the institutional care context, which operated based on the exploitation and marginalization of these two distinct yet interconnected groups of multiply marginalized women. Their interdependence was, in many ways, structural—the care dyad needed each other to survive. However, the care workers and old women with dementia were able to create and maintain care relationships that aligned with feminist disability studies politics of relationality and time by centering collectivity, shared moments of connection, and making time for and giving time to each other, even in a context that constructed them as "out of time." In this regard, perhaps the gifts of time in the dementia unit, like crip time, are part of Alison Kafer's (2013) vision for "more accessible futures." In the next chapter, I further explore the care relationships between the old women with dementia and the care workers by forwarding the theory and practice of "dementia time."

VI. (RE)BUILDING RELATIONSHIPS THROUGH DEMENTIA TIME

Although the lived experience of dementia is diverse, old people with dementia often experienced difficulty with memory, confusion of time and place, and disorientation. As normative time is highly associated with the ability to linearly bring the past into the present, to be aware of what, when, and where an event has occurred (or is occurring), and to align one's self with the "objective" reality, dominant understandings of time are highly oppressive for people with dementia. In the community and in institutions, people without dementia regularly try to "correct" and reorient people with dementia, or disengage if the person with dementia is disoriented, confused, or fails to "make sense." However, crip time and queer time provide theoretical and cultural approaches to rethink interactions and relationships with people with dementia. In this chapter, I forward dementia time, a temporal dis/orientation that seeks to "explode time" (Kafer, 2013) by focusing on the moment in time and place, maintaining rhetoricity and affirming personhood, acknowledging and respecting situated realities, and engaging in a politics of flexibility, creativity, and collective care. I contend that dementia time is an extension of crip and queer time that disrupts normative time and thus holds liberatory potential for old people with dementia and others with mental disabilities. Prior to examining how we might augment crip and queer time to apply to people with dementia and other mental disabilities, I want to further illustrate how the dominant temporalities in the dementia unit were disabling to the old women with dementia.

A. **(Dis)orienting Temporalities**

As clock time was the foundation of institutional time and bureaucratic time, the dementia unit at Cedarwood Care Center had multiple clocks accessible to staff and residents. The clocks were present in each wing's common area and in the community/dining room. For the care staff, the clocks served the purpose of ensuring the

staff were tracking the time and their care work aligned with the routine established by the institution. For the old women with dementia, the clocks were intended to be a “re-orientation” tool, yet occasionally caused disorientation. The clocks were not typical clocks, but rather specialized clocks known commonly as “Alzheimer’s clocks” or “dementia clocks” (shown in Figure 5: Dementia Clock).

Figure 5: Dementia Clock

Photo of a dementia clock on a wall. The clock displays the day of the week (Monday), the date (the 3rd) and the month (June) as well as the time (12:56 p.m.) in analog format.

These clocks usually display the time in analog format, the day of the week, the month, date, and year. This information is often displayed in large print. Some also include the time

of day (e.g., morning, afternoon, night). According to Archer (2017), dementia clocks are necessary because:

> Patients with Alzheimer's, memory loss, or dementia thrive on structure and routine. A loss of awareness of the time or date can send a patient into a panic, and can tax caregivers who grow weary of reminding patients of the day or time over and over. (para 6)

Thus, clocks, and particularly dementia clocks, are understood as an "orienting tool" for people with memory loss—a way to assist them in aligning themselves with normate time by remembering the present day and time. They are also promoted as a way to reduce caregiver "burden," as they theoretically allow the person with dementia to orient themselves using the clock rather than asking repetitive questions (Alzheimer's Store, 2020). The Alzheimer's Store (2020), which sells a variety of dementia clocks, provides a "tip" for caregivers: "Always remind [the person with dementia] of the date, day, time, and place to maintain orientation" (para 2). The store then suggests dementia clocks are one of the best ways to do this, noting that they "help patients regain some of what they have lost" (para 6). Again, this emphasis on orientation to normative time reflects the Kafer's (2013) conceptualization of curative time—although people with dementia cannot be cured, they can be pushed toward normalization through technologies such as dementia clocks. This framing of dementia clocks forwards the belief that time—and specifically the "accurate" time—is essential to well-being and the ability to maintain a grip on "reality."

Accordingly, clocks serve as the basis for a cognitive screening tool called the "clock drawing test," which is a widely used screening tool to predict or evaluate the development or progression of Alzheimer's and other dementias (Amodeo et al., 2015). The test is administered by a clinician providing a person with either a blank piece of paper or a piece of paper with a circle drawn on it and then instructing them to depict a clock showing a time,

such as 10 minutes after 11 (Heerema, 2019). They then evaluate the drawing for critical test errors which include “wrong time, no hands, missing numbers, number substitutions, repetition, and refusal” (Reuben, 2009, p. 2688). Such errors indicate a neurological “problem” is developing or worsening. As Archer (2017) observed, “There might be no clearer metaphor for mental clarity than [the] clock” (para 1). Hence, clock time and the capacity to comprehend and follow it is intimately connected with compulsory able-mindedness and compulsory youthfulness. As previously discussed in Chapter IV: Dominant Temporalities in the Dementia Unit, these compulsory systems construct able-mindedness and youthfulness as normal and desirable, and thereby position mental disabilities as abnormal and abject (Gibbons, 2016; Kafer, 2013). The inability to recognize or conform to clock time marks old people with dementia as outside the bounds of normalcy, and efforts to “reorient” them to clock time seek to move them back towards those boundaries, even though they will never be understood or treated as normal again.

In the dementia unit of Cedarwood Care Center, the dementia clocks were often referenced at the start of activities to reorient the residents. A few times, the dementia clock was incorrect, and chaos ensued.

> *For the month of June, Reyna, the Activity Director, has put together trivia that references people born in June or historical events that occurred in June. Like many of Reyna’s planned activities, this activity requires residents to be able to recall information and respond verbally with the answers, and so only a small group of residents has the capacity to participate. As usual, Reyna starts by asking what the day of the week and date are. Fauna looks at the dementia clock and then confidently declares, “Wednesday, June 6!” It’s Tuesday, June 5 so, confused, I too look at the clock—and realize it is fast by one day. “No, it is Tuesday,” Reyna responds. She follows the residents’ gaze to the clock, and observes, “I think this clock is wrong.” Fauna and Alice look at the clock again. “No! It is Wednesday!” they insist. “No, it is Tuesday,” Reyna repeats, exasperated. “I thought it was Wednesday!” Fauna exclaims. She turns to Guadalupe, the CNA who is sitting with the group. “What day is it?” she demands. “It’s Tuesday,” Guadalupe responds. Fauna frowns and looks back at Reyna, clearly unconvinced. “We* must *change the clock!” Reyna declares.*

Other times, the clocks agitated the old women with dementia when they did not align with their realities.

> *Isabelle asks about the time. Fauna looks at the clock and reads "4:00 p.m.", but the clock points to 12:20 p.m. Reyna interjects and tells Fauna, "No, it is still early." Fauna gets flustered. "But..." Reyna interrupts, "No, it's early, not even 12:30 pm." Fauna is getting more frustrated. "I know but..." "Don't worry about the time," Reyna says. "I know, but..." "Don't worry about it. Just trust me." "I do but..." "Just don't worry about the time." Fauna gives up and throws her hands in the air.*

> *Lucille frequently refuses to come to dinner and often has to be coaxed to come. She is typically sundowning[35] around 4:30 p.m., and so she firmly does not believe it is time for dinner. A loaner CNA does not know this about Lucille and tells her to come to the dining room for dinner. "What?" Lucille asks in disbelief. "I am not coming to dinner; I just ate breakfast!" "No, it's dinner, look at the clock!" The CNA tells her. Lucille looks at the clock and yells, "That clock is wrong! It's not dinner!" She returns to her room and shuts the door.*

In such cases, the "reorientation" clocks did not have the intended effect and worse, caused the old women with dementia distress. However, a very different outcome occurred when the temporal realities of the old women with dementia were respected and affirmed:

> *The CNAs are starting to transport residents to the dining room for dinner. Lucille leaves her room and greets Meera with a smile. Meera says to her, "Hey there, shorty!" "Haha, yes, well, look at you! You're short too!" Lucille puts her arm around Meera and kisses her on the forehead. "I love you!" Lucille says. She then asks Meera, "What can I do for you?" "Let's go to the dining room!" "The dining room?" "Yes, for breakfast!" Meera tells her. Meera, aware that Lucille is likely sundowning, knows better than to reference the clock or try to argue that it is dinner time. "Oh, okay," Lucille agrees. "But where are my children?" "They're waiting for you, let's go!" Meera replies. Lucille happily heads to the dining room with her.*

In this interaction, Meera was practicing what I have termed dementia time. In this chapter, I explore how the concepts of crip time and queer time might be expanded and used to both challenge dominant conceptions of dementia and generate different interactive moments and relationships between people with dementia and other mental disabilities and those

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[35] Sundowning refers to confusion, disorientation, and sleep disturbances people with Alzheimer's disease and other forms of dementia experience later in the day, usually at dusk or at night. Sundowning can also be accompanied by anxiety and agitation. Factors that may contribute to sundowning include mental and physical exhaustion, an "upset" in the internal body clock causing a mix up between day and night, or insufficient sleep (Alzheimer's Association, 2020c).

without. In doing so, I advance dementia time, which emphasizes focusing on the moment in time and place, and enacting flexibility and creativity to care for one another as moments pass and needs change.

B. **Crip Time**

Crip time is the part of disability culture that challenges normative views and constructions of time. Kuppers (2014) drew from the work of Garland-Thomson (2002) and referred to these dominant systems of time as "normate time" (p. 29). Within the dementia unit, clock time, institutional time, and bureaucratic time served as the basis of normate time. Conversely, Kuppers (2014) referred to crip time as a form of "temporal shifting," in recognition that normate time is difficult, and indeed, oppressive for disabled people (p. 29). Crip time asks us to change how we view and approach time rather than attempt to force disabled bodyminds to conform to "normate time" (Price, 2015; Samuels, 2017). As Kafer (2013) wrote:

> Crip time is flex time not just expanded but exploded; it requires reimagining our notions of what can and should happen in time, or recognizing how expectations of "how long things take" are based on very particular minds and bodies…Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds. (p. 27)

Thus, crip time promotes softness, a shifting of pace, and flexibility. Crip time is at times understood as a slowing down or speeding up of time but also includes more "radical forms of bending and folding" (Price, 2017, p. 157). As previously discussed, crip time can also serve as time travel, unsettling the ways disability and aging intersect throughout the life course or warping the ways time is perceived and experienced (Samuels, 2017). By "exploding" time, crip time offers a multitude of possibilities for challenging normative

constructions of time. As characterized by Price (2017) and Samuels (2017), crip time allows disabled bodyminds to be in space and time *as we are*, and thus potentially becomes a complex form of liberation.

C. **Queer Time**

Like crip time, queer time also disrupts normativity and dominant constructions of time. Kafer (2013) advances that crip time and queer time are deeply intertwined, noting:

> One could argue that queer time is crip time, and that it has been all along…Shifts in timing and pacing can of necessity and by design lead to departures from "straight" time, whether straight time means a firm delineation between past/present/future or an expectation of a linear development from dependent childhood to independent reproductive adulthood. (p. 34)

Thus, queer time turns away from what Halberstam (2005) terms the "narrative coherence" of the life course. In other words, queer time disrupts the idea that our lives should have a set trajectory of birth, childhood, adolescence, young adulthood, marriage, reproduction, child-rearing, retirement, and death—a trajectory rooted in compulsory heterosexuality, compulsory able-bodiedness/able-mindedness, and compulsory youthfulness (Gibbons, 2016; Kafer, 2013; McRuer, 2006). According to Freeman (2010), the structured life course and resulting age norms around the "right" time to enter life stages such as partnering, parenting, and working, are representative of chrononormativity—a dominant temporality that seeks to maximize productivity under capitalism. She argued that queer temporalities resist and undo chrononormativity. Hence, queer time challenges dominant scripts related to progress, linearity, development.

Within the context of challenging the normative, linear life course, queer time challenges futurity, or the "investment in and attention to the future or futures" (Kafer, 2013,

p. 28). Rejecting futurity forces us to focus on the present, rather than looking forward to the future. Halberstam highlights how the AIDS crisis led queer communities to focus on “the here, the present, the now” (Halberstam, 2005, p. 2). As Kafer (2013) observed, “The queer time of the epidemic deflects attention away from the future altogether, attending only to this moment, finding urgency in the present” (p. 35). Given that old people with dementia are perceived as having no future and an idiosyncratic connection to the past, the present becomes an important opportunity for connection.

Furthermore, José Muñoz (2009) affirmed queer time’s focus on the present but urged an understanding of the present as a site of future-making. He wrote, “Queerness should and could be about a desire for *another way of being in both the world and time*, a desire that resists mandates to accept that which is not enough” (p. 96, emphasis added). In other words, queer time, like crip time, is about reimagining the world and working toward a future that is more fluid, flexible, and liberatory—an intention shared by dementia time.

D. **From Crip Time and Queer Time to Dementia Time**

By considering dementia as a part of crip and queer temporalities, we can push these resistant forms of time further. The flexibility of crip and queer time is important to consider in the context of dementia. Within the dementia unit, the needs of people with dementia were changing from moment to moment. This occurred partially because although dementia is overall progressive in its course, people’s experiences of memory, orientation, and sense of self, time, and place vary and shift throughout the day, and subsequently, their needs change. However, scholarship on crip and queer time does not frequently explicitly engage with other aspects of normate time that affect people with dementia and other mental disabilities, such as memory, coherence, and rationality.

I extend crip and queer time by forwarding a theory of "dementia time." Dementia time involves focusing on a particular moment in time and place and remaining flexible as moments pass and needs change. In normate time, individual moments are connected through a linear and progressive sequence, whereas in dementia time, individual moments may be self-contained, nonlinear, intermittent, irrational, and idiosyncratic - *yet they are no less meaningful or valuable.* Within the dementia unit of Cedarwood Care Center, dementia time served as a site of connection, solidarity, and relationship (re)building between the old women with dementia, the care workers, and me. Thus, dementia time is a site of social potentiality. Dementia time asks us to consider: (a) how we might perpetually (re)build relationships with people with dementia and other mental disabilities by focusing on the moment; (b) how to maintain people with dementia and other mental disabilities' rhetoricity in order to practice inclusion and affirm their personhood; (c) how people with dementia and other mental disabilities may be operating in situated realities that resist dominant conceptions of time and reality; and (d) how we can emphasize a politics of collectivity and care with people with dementia and other mental disabilities.

E. **A Note about Language**

While conceptualizing the neologism dementia time, I struggled to settle on a term, as I questioned how using the diagnostic, biomedical label of "dementia" would fit into crip politics. "Dementia time" has limits as it invokes dementia as we presently understand it, which is predominantly according to a biomedical model in Western societies, and feminist disability studies has been critical of diagnostic language as it further medicalizes disabled people. Indeed, the word dementia comes from the Latin word, de mentis, which means "out of one's mind," and this characterization of people with dementia, as "out of their minds" and as "the living dead" has contributed to their dehumanization

(Behuniak, 2011). However, the classification of people with dementia as “out of their minds” connects people with dementia to people with a broad spectrum of mental disabilities. Here, I use Price’s (2013) conceptualization of mental disability, which ze uses to draw connections between people who are labeled with various impairments of the mind, such as learning disabilities, intellectual disabilities, and psychiatric disabilities. Similar to people with dementia, those of us with these labels are thought to be “out of our minds” in various ways, as we communicate, feel, relate, and act in ways that challenge societal constructions of normalcy.

I have considered, and in other contexts, used the phrase “demented time” (Dunford, Yoshizaki-Gibbons, & Morhardt, 2018; Yoshizaki-Gibbons, 2018b). I am interested in exploring demented as a radical, political coalitional term that more directly and broadly applies to people with diverse mental disabilities. “Demented time” more clearly fits into crip politics, rejects diagnostic language (which is an important project of feminist disability studies), and attempts to reclaim a term that has been used to dehumanize those of us labeled as “out of our minds.” As Floyd Skloot (2003), a writer and activist with dementia who seeks to challenge the way we understand what it means to be “demented,” noted: “When demented breaks down into ‘de’ for ‘out of’ and ‘ment’ for mind—literally ‘out of my mind’—I interpret the verbal construction as having positive connotations. Not looney, but liberated. Forced out of my mind, forced away from my customary cerebral mode of encounter, I find myself dwelling in wilder realms of sense and emotion” (pp. 21-22). However, even though I seek to apply the term demented to time and do not advocate for referring to people as demented, demented is a loaded term. The vast majority of people with dementia have rejected it. These factors make it a complicated issue. Given that I am not a person with dementia, I have elected to use “dementia time” in the context of this project.

Although relying on diagnostic language may make solidarities between people with mental disabilities less likely, I am hopeful that dementia time will serve as a unifying concept. Due to my relationships with people with dementia, I am keenly aware that people with dementia and other age-related impairments have been ignored in and excluded from the majority of disability scholarship and activism—an issue that must be addressed (Yoshizaki-Gibbons, 2018). Furthermore, the desire to apply dementia time beyond people with dementia also arises out of my own positionality, for although I do not have a diagnosis of dementia, I find the tenets of dementia time are meaningful to me, as a person with mental disabilities. Dementia time holds coalitional potential, as it connects people with a diverse number of mental disabilities who are labeled as "out of our minds." Perhaps if we understand dementia as Power (2017) proposes, as a “shift in the way a person experiences the world around them,” these connections will become even stronger, and we can further envision the ways dementia and dementia time are situated within crip politics (p. 9).

F. **The Tenets of Dementia Time**

In what follows, I forward four tenets of dementia time: (a) focusing on the moment; (b) maintaining rhetoricity to practice inclusion and affirm personhood; (c) acknowledging and respecting situated realities; and (d) emphasizing a politics of collectivity and care. In the practice of dementia time, these tenets overlap, merge, and meld. I include stories of my experiences sharing interactive moments with old people with dementia within the dementia unit, in order to center them and delineate each tenet. Additionally, I discuss moments in which the care staff or family members chose to engage in dementia time, or chose not to, and discuss the effects these different choices had the individuals with dementia.

1. **Focusing on the Moment**

An important tenet of dementia time is focusing on the moment. By moment, I do not necessarily mean the present. People with dementia and other mental disabilities may live simultaneously in multiple timescapes - past, present, and future. As a trauma survivor who has experienced flashbacks, there have certainly been times in my own life where I am concurrently in the past and present. There have also been times when I am unable to meaningfully engage with the past and need to fixate on the present. Similarly, people with chronic pain may desire to focus on the future or past because they are experiencing pain in the present (Vidali, personal communication, 2017). As these various bodymind experiences demonstrate, being "in the moment" does not necessarily fully align with being "in the present." Consequently, I use moment to mean an event, happening, or experience, which can be oriented to various points in time or situated realities.

Due to its focus on being in the moment, dementia time asks us to suspend our ideas about memory and the assumption that memory is an essential aspect of building and maintaining relationships with others. Generally, we often rely on memory in our relationships - we use memory to form a narrative of the relationship and we often engage in relational activities such as telling stories about past events or reminiscing (Basting, 2009). However, dementia time asks us to think about how we might perpetually (re)build relationships with people with dementia by focusing on feelings, thoughts, and ideas in that moment in time rather than the ability to access and communicate memories.

To illustrate this point, I would like to share a story from my field notes about an interaction with Marlene, an 88-year old woman with dementia.

> *I am sitting with Marlene at dinner. Across the room, another resident, Aileen, is receiving her medication. "Go away, I hate you!" Aileen yells at the nurse. Marlene looks up. "I hate you? Wow!" "Does that bother you Marlene?" I ask. "Yes, I am so*

> *angry!" "That's understandable," I tell her. "I just want to get out of here!" She begins to sob. "I mean, I just can't take this anymore. I can't. I want to go home." "I'm sorry, I know you want to go home." I rub her back. "Yes, I want to go home! They're just junking around. I'm with my kids. You can go be with your wife or phone or whatever. I just feel like I have to get into my house." "What do you like about your house?" I ask. "Well, you were there. You saw it!" Marlene responds. "Oh right. It was nice!" I answer. "Yeah! It was everything." Marlene says. "Nothing good, and nothing bad. It's all there!"*

During this interaction, I repeatedly sought to connect with Marlene - even if I was not quite sure what she was trying to communicate, such as when she told me I could go be with my wife or my phone. I validated her shifting feelings, from anger to sadness. I asked her a question about her home that invited her to offer an affective, emotional response rather than a description based solely on recall. And when she told me I had been there I affirmed her experience of my presence in her home. Rather than require individuals with dementia to access and communicate accurate memories as a part of relationship building, dementia time asks us to connect with the person with dementia in that moment in time.

Another key part of (re)building relationships by focusing on the moment is understanding that relationships with people with dementia and other mental disabilities may develop nonlinearly and in surprising ways. Relationships might always start from the same place, and that place might be the introduction. Some days relationships may be well-developed in a person's mind, and other days they may be absent. In some instances, we may represent a different person and thus a different relationship. For example, the majority of the participants did not remember me day-to-day, though some certainly verbally and nonverbally expressed that I became familiar to them. Each day in the dementia unit, I would introduce myself to many of the people with dementia as if we had never met. If they communicated verbally, I would engage them in repetitive and similar conversations around topics I knew were important or interesting to them, such as family, politics, or fashion. This approach draws from Kafer's (2013) and Basting's (2009)

assertions that disability and memory are relational—in other words, occurring between bodyminds. The interactions were virtually the same every day, yet at the same time they were often surprising in some way and required creativity and a politics of care to navigate. The individuals with dementia and I were able to relate and connect in various ways each time, in the moment. Although the interactions were not always preserved in their memories, the moment was meaningful for both of us.

Likewise, one of the primary ways the care staff engaged in dementia time and built relationships with residents with dementia was through having recurrent interactions on a regular, ongoing basis.

> *When it is Ciera's turn to watch, she often sits by Mable. Mable is one of the few Black old women in the dementia unit, and Ciera, who is also Black, fondly refers to her as Granny. Nearly every day, Ciera asks Mable the same question about her daughter: "Granny, how is Pamela?" Sometimes Mable responds, "Good!" Other times just says, "Yeah!" or she vocalizes. Regardless of how Mable answers, Ciera always tells her, "That's good, tell Pamela I said hi!"*
>
> *For the entire time Meera has known and cared for Miles, he has referred to her as Susan. Meera does not know why Miles believes that is her name or who Susan is to Miles, but she always affirms it. Today when Meera comes in for the start of her shift at 3:00 p.m., she notices Miles sitting and approaches him. As usual, she looks him in the eyes, and says, "Miles! It's Susan!" She squeezes his shoulders. He smiles at her.*

Ciera explained how she bonded with the residents for whom she cared by learning about them as individuals and then using what she learned again and again:

> *I talk to 'em. I talk too much! I'm there. I ask family members, I watch for patterns, I ask the residents. So, I have a resident, Vladimir. And he speaks nothing but Russian, but…his wife told me he was an engineer. So, he likes to look at paintings and stuff. So, every day I just talk to him about drawing or paintings or his daughter that lives in New York. And Vladimir likes to laugh. He knows that I can't speak Russian good. So, when he asks me a question, I just say, 'Da! Da!' and whenever it's not a yes or no question, he laughs at me. It's fun.*

Ciera approached her relationships with Mable, Vladimir, and the other people she cared for cyclically and enjoyed the bonds they formed through a series of moments, despite having what outsiders might characterize as repetitive or redundant interactions. Thus, dementia

time asks us to focus on the ongoing (re)building of relationships rather than the person's ability (or inability) to access memories. In doing so, we can acknowledge that the important aspect of the interaction is the connection being built between oneself and an individual with dementia or other mental disabilities in that moment in time.

2. **Maintaining Rhetoricity to Practice Inclusion and Affirm Personhood**

Another tenet of dementia time is maintaining the rhetoricity of people with dementia and other mental disabilities in order to practice inclusion and affirm personhood. The voices of people with dementia are often not acknowledged or respected (Bruens, 2013). People with dementia frequently report feeling ignored, dismissed, or avoided, particularly when they cannot remember what has happened in the near or distant past or when their expressions do not "make sense" to the people around them (Beard et al., 2009; Harris, 2002). Sabat (2001) argued that selfhood exists through engagement with others, but people with dementia are often denied this because their attempts at connection are ignored or refused by others. This rejection is often rooted in people's desire to hold on to dominant "rules" of time and interaction—people struggle to engage with someone who fails to "make sense." This inability to "make sense" results in a denial of rhetoricity, or the ability to be received as a valid human subject (Prendergast, 2001; Price, 2011). Prendergast (2001) made a similar observation about people diagnosed with schizophrenia, noting that they are regulated to a "rhetorical black hole" and consequently, their words are viewed as not meaningful or manifestations of their symptoms (p. 53). People with dementia are primarily denied rhetoricity because of bodymind experiences associated with dementia, such as memory loss, disorientation, or aphasia. Consequently, they may not "make sense" to those around them according to dominant "rules" of communication. As Price (2011) explained: "The failure to make sense, as measured against and by those with

"normal" minds, means a loss of personhood" (p. 26). However, if we suspend the presumed need to bring the past into the present, we can recognize that the important aspect of dialogue with people with dementia is not logic, linearity, coherence, or rationality, but rather listening, engaging, and establishing connectivity. This story about Sylvia, an 81-year-old woman with dementia, exemplifies this tenet.

> *Sylvia looks over her shoulder at me. "Honey? Can you help me with something?" I approach her. "Yes, Sylvia, what is it?" "Can you eight wait great to that?" I am unsure what Sylvia would like me to do, but I agree. "Oh yes, of course!" I answer. "Just when you have the tone." "No problem," I reassure her. "Should I write it here for you?" Sylvia gestures to her hand. "Yes, that would help me remember," I nod. Sylvia mimes writing a note on her hand. "Thank you, Sylvia!" "Thank you!" Sylvia responds. She then grabs my hand, and adds, "I took the ship, the friend ship!" "Well friendship is always good to have!" I nod. "Right!" Sylvia smiles and laughs.*

As this interaction demonstrates, dementia time asks us to consider how a person "makes sense" in that specific moment and context. In this moment, I maintained Sylvia's rhetoricity by taking her request seriously and agreeing. Sylvia felt connected to me after she asked for help and I agreed. She then shared she "took the friend ship," which made sense as an expression of friendship in this context. Rather than demanding that people present linear, coherent, rational narratives, dementia time asks us to consider how a person "makes sense" in that specific moment and context. Doing so will require recognizing that dominant understandings of rationality are not necessary to sharing meaningful and valid interactive moments. In other words, rather than demanding that "reliable" rhetors access memories and present linear narratives of the past leading up to the present, dementia time asks us to consider how a person "makes sense" in that specific moment and context. Hence, each moment may have its own "sense."

I observed the care staff employing this tenet of dementia time often. For example, one time as I was walking with Sylvia to the dining room, we passed Fiona, one of the cleaning staff. "How you doin' Sylvia?" she asked. "I'm just pobbling!" Sylvia smiles. "Well

that's good! Keep on pobblin' Sylvia!" Fiona replied. This aspect of dementia time requires us to expand our understandings of what counts as "making sense," and recognize that people might make sense within their own frameworks, regardless of whether those uniform with our frameworks. In doing so, we can maintain rhetoricity, establish connection, and affirm personhood.

3. **Acknowledging and Respecting Situated Realities**

Another tenet of dementia time is the importance of attending to situated realities. Dominant narratives dictate that time and reality are often viewed as interconnected objective and linear truths. People without dementia often attempt to "reorient" people with dementia to what they view as the "correct" day and time and "true" reality (Beard, 2004). Yet, as Price noted, this emphasis on rationality is oppressive to people with mental disabilities (Price, 2011, 2015). Acknowledging situated realities allows us to focus on the ways in which realities emerge from individuals, and therefore it is their perceptions of reality that are important, regardless of whether their reality aligns with our reality.

As Beard et al. (2009) stated, "We can refrain from enforcing *our* cognitive reality by letting go of normative expectations and 'joining' people with dementia in their worlds" (p. 228). This tenet seems to connect with the idea of "therapeutic lying" in dementia care, which involves telling a "good lie" or "white lie" to alleviate a person with dementia's distress (Casey et al., 2019). However, I want to challenge the idea that respecting a person's situated reality is "lying." Framing this form of engagement as a lie holds on to the idea there is a singular, objective, and "true" temporal reality. If one can acknowledge and be responsive to situated realities, one can understand that people with dementia and other mental disabilities may be operating within their own reality and temporality in that moment

that is meaningful. To demonstrate, I would like to share another story about Sylvia from my field notes.

> *Sylvia has aphasia and cannot communicate much about her life in ways that I can understand. She has two children, but they never come to visit. One day, out of curiosity, I search her full name on the internet. Only one relevant finding appears - a photo of a grave in a nearby cemetery. There is a stone for Sylvia, with the date of death left blank, and a stone for her husband, Thomas, who died nearly 18 years ago. Sylvia often mentions someone named "Tom," and I realize she has been referring to her husband. The next time I see her, I ask, "Sylvia, how is Tom?" Her face lights up. "Oh, he is fine!" she laughs. "He's right there!" she gestures across the room. I look and laugh. "Oh, how silly of me, I should have just asked him myself. I'm sorry!" "That's okay!" Sylvia smiles, and pats me on the cheek. "He's wonderful." "He really is," I agree.*

Dementia time asks us to cast aside expectations regarding a singular, objective reality, and focus on the meanings expressed in situated realities. In my interaction with Sylvia, I focused on her situated reality: Sylvia experienced her husband Tom as being present with her in the room and doing well, which I affirmed. In the dementia unit, old women with dementia would often ask questions or talk about loved ones—particularly their mothers or partners—as if the person was still alive. Some of the care staff would respond by informing the person that their loved one was dead. They did not do this to be cruel, but because it was the "objective" reality. Despite their intent, such a response would distress the individual with dementia, at times severely. Here is one such interaction between Laurelle, a 78-year old woman with dementia, and Alyia, a CNA:

> *Laurelle announces, "I have a problem." Alyia responds, "What is your problem? I am going to resolve it. Tell me." Laurelle says, "My mother is sick." Alyia feigns shock. "Your mother? She's alive?" Laurelle responds evenly, "Yes, she is alive." "How old are you?" Alyia asks. "I don't know!" Alyia tries to force Laurelle to reason. "You are 78. So how can your mom be alive if you are 78?" Laurelle does not respond, but hangs her head, defeated.*

Conversely, other care staff would affirm the person's experience of their loved one being alive and would respond in a way that respected their situated reality. Here is another example with Laurelle, this time interacting with a different CNA, Serena:

> *Laurelle stands and begins to walk. Serena gently tells her, "Laurelle, sit down." Laurelle responds, "I have to find out!" "About what?" Serena asks. "My mother," Laurelle says sorrowfully. "I will find out for you," Serena says. Laurelle sits, but after a few moments, stands again. "Sit down please," Serena calls. Laurelle retorts, "I don't want to sit!" "Why?" Serena asks. "I want to look for my mother!" "Let me look for her. I'll let you know," Serena responds. "Okay," Laurelle agrees, and sits.*

Such responses would help the person with dementia feel comforted and reassured. By acknowledging and responding to situated realities through dementia time, we can enter the realities of others, and share meaningful and significant moments in which we are all included.

Dementia time also asks us to envision the ways in which situated realities may serve as a form of potentiality for a less painful or traumatizing past, present, or future. This interaction with Lucille, an 89-year-old woman with dementia, elucidates this aspect of dementia time.

> *Lucille is sitting outside the nurse's station one afternoon. I stop to greet her. "Hi Lucille, how are you?" "Hello, dear," she responds. "I'm okay. I'm just waiting to talk to someone." "Oh, do you need something?" I ask. "I'm waiting to talk to the man. I'm leaving tomorrow, I hope." None of the staff has reported that Lucille is being discharged, so I am fairly certain she will continue to stay in the dementia unit, but I respond, "Oh, how wonderful! Where you are going?" "Home!" she exclaims. "I am going home!" "Oh, well we will miss you," I tell her. "Thank you. I want to get out of here. I've lived here a long time so I guess I'm used to it but I need to get out of here, I want to go home." "That's understandable," I tell her, adding, "Everyone here wants to go home." Lucille continues, "Yes, absolutely, and I need to get my boys ready for school. My middle son, he will be going back soon, and my oldest son too." "Oh yeah, it's that time of the year where everyone is going back to school," I say. "Yes, I need to get home." Lucille then switches gears. "I need to get home because I'll be going back to school." "That's exciting!" I tell her. "I just started school again yesterday." "Oh, where?" "UIC." "What are you studying?" "I am working on my Ph.D. in Disability Studies." "Oh good for you!" Lucille smiles and claps. "Well I hope everything works out with your schooling," I tell her. "Thank you honey, you too!" she beams.*

Lucille's situated reality merged her past, present, and future. Although her present situation was living in the dementia unit, she imagined a future in which she could go home, for a reason connected to her past – to get her sons and herself ready for school. Within the confines of the dementia unit, people with dementia constantly expressed a desire to

escape institutionalization and go home, and again, some staff focused on the objective reality by telling them, “This is your home,” or, “You live here now.” This strategy often caused the person with dementia desiring to go home to be in even more pain, and many responded with arguing, crying, and sometimes aggression as they expressed their despair. Conversely, when others respected their situated realities as part of dementia time and affirmed their belief that they would be going home, the people with dementia felt more content and at peace with their difficult present. In this way, dementia time serves as way to cope with pain and trauma by entering and affirming a situated reality. As a result, it emerges as a way to collectively imagine a different, more liberating past, present, or future.

4. **Emphasizing a Politics of Collectivity and Care**

All of the stories I have shared thus far highlight the final tenet of dementia time, as they each forward a politics of collectivity and care. My focus on relationships between people with dementia and people without dementia draws from a vision of collective care and access—of moving toward being radically together (Price, 2017). The dominant imaginary of care for people with dementia is one of total and utter dependency, in which people with dementia are completely dependent on a caregiver for their survival and well-being. Indeed, that is one of the major justifications for confining people with dementia in dementia units of nursing homes until they die. People with dementia, particularly advanced dementia, are often not perceived as capable of contributing to care relationships in ways that are traditionally understood as meaningful. In fact, some depict dementia as a process of increasing dependency, with people with dementia becoming completely dependent on others for care in the later stages (Volicer, 2005).

By emphasizing a politics of collectivity and care, we can (re)imagine interactive moments that are interdependent and focus on each other's needs and our shared humanity. This story about Marlene from my field notes demonstrates how dementia time can result in shared moments of care.

> *Marlene begins crying at dinner because she does not want any more of her food. "It's okay, Marlene," I try and comfort her. "It is?" she asks. "Yes! Just eat until you are done." "Oh, thanks kiddo!" Marlene puts her hand on my cheek. "Thanks so much." "You're welcome. You're having a hard day?" "Yes, I am," Marlene cries. "It's just so hard. It's all messed up in the car." She takes a bite of peaches. "I just can't find it!" she cries harder and places her head on the table. I tear up a little bit, as I feel Marlene's pain meld with my own. "I know what you mean. It's okay to have hard days. I have lots of hard days. I am having a hard day today," I tell Marlene. "You are?" Marlene lifts her head, looks me in the eyes, and smiles softly. "I certainly have mine. Thank you honey," she says. Marlene then leans across the table and presents her forehead for me to kiss, which I do, and I relish in how comforting this tender moment is for both of us.*

In this moment, Marlene and I were engaging in an interdependent, caring relationship. Although Marlene and I were not engaging in normative communication or "socially acceptable" behavior, we both had our needs met in the moment. We can challenge dominant constructions of "totally dependent" relationships by highlighting and appreciating the ways we can care for each in dementia time. Thinking through my time in the field, I appreciate all the ways care moved between people with dementia and people without dementia. The people with dementia would empathize with and comfort the care staff, such as when Ramona recognized that Evie "was working hard," or when Lucille told Karina she thought she should get paid more. They would also express affection toward the care staff—holding their hands or telling them they loved them. I observed and took part in many other examples of constantly (re)building relationships in dementia time, by respecting each other's feelings and pain, connecting through conversations that made sense in that moment (such as "taking the friend ship") and laughing together.

As Price (2015) stated in her work on caring for bodyminds through a feminist disability studies ethic of care:

> Care means moving together and being limited together. It means giving more when one has the ability to do so, and accepting help when that is needed. It does not mean knowing exactly what another's pain feels like, but it does mean respecting each person's pain as real and important. Finally, care must emerge between subjects considered to be equally valuable (which does not necessarily mean that both are operating from similar places of rationality). (p. 279)

In this conceptualization of care, Price emphasized people who are considered equally valuable. This "value" is not connected to their supposed capacity for rationality or their ability to give or contribute to the needs of others in ways traditionally recognized as "care," but rather to their personhood, and the shared need all humans have for support. This conceptualization of care guides my thinking as I work through how we build on crip time to address the unique experiences and needs of people with dementia and other mental disabilities. Dementia time centers collectivity by focusing on the needs of both individuals in the interaction or relationship, at that moment in time. Rather than viewing needs as somewhat static or stable, it helps us embrace the fact that needs are changing moment to moment and the way care occurs is changing moment to moment. If we can focus on the moment, we can better engage in a politics of collectivity and care with people with dementia and other mental disabilities.

G. **The Complexities of Dementia Time**

Although dementia time encourages us to rethink how we interact with people with dementia and other mental disabilities, I do not want to romanticize dementia time. While, like crip time, it can serve as a form of liberation, it is marked by complexities and challenges.

1. **Dementia Time as a Site of Containment and Control**

For instance, although the care workers predominately engaged in dementia time with the residents to connect with them, ease their pain or suffering, and build relationships, dementia time sometimes served as a site of containment and control.

> *Anthena suddenly stands up from her wheelchair and starts to walk. Anthena is labeled as a "fall risk," and so she is not permitted to walk independently at all. Ciera, a CNA, asks, "Miss Anthena, can you please sit down?" Anthena looks Ciera directly in the eye and sternly demands, "I want to talk to your mother!" Ciera coolly responds, "Well, my mother wants you to sit down." Anthena stares at Ciera for a moment and then says, "Oh. Okay, then!" and sits back down.*

In this case, Ciera used dementia time but in a way that restrained Anthena and allowed Ciera to fulfill her job duty of ensuring the residents stayed seated and did not fall. The care workers used dementia time to control the residents most often when the residents were struggling with feelings of confinement and expressing a desire to go home. Whereas some care workers would try to explain to the residents that they now lived at Cedarwood Care Center (which virtually never went well), others would use dementia time to affirm to the residents that they would be going home soon, they just could not go right away.

> *Harry begs, "Please let me go home." "I want to go home too," Serena empathizes. "Why are you doing this to me? Help me, please, I wanna go home!" "I'm not doing anything to you," Serena responds. "Yeah, I know you're not doing anything, let me go home! Why are you doing this to me? Why? Oh shit, please, god dammit! Help me! I wanna go home! Just let me go home!" Howard stands and tries walking off on his injured leg. Ashanti immediately guides him back to his wheelchair. "Harry, you can't stand, your leg is hurt." Harry yells, "What do you mean I can't stand?! I'm not a little baby!" Ashanti tells him, "Harry, listen. If you sit quietly, I will take you home. As soon as I get off work."*

> *Isabelle is distressed. "I want to go home! I want to go home." When no one responds she begins yelling, "Hello! Hello! Hello! Take me home!" She then sees Brenda walking by and gestures her over, "Excuse me, how can I go?" "Where do you want to go?" Brenda asks. "I want to go home!" "Well, it's awfully cold outside so I don't really think we can take you home right now, but we could take you to your apartment until the weather is better." "Fine," Isabelle agrees.*

In these situations, the care workers were still respecting the residents' situated realities in a way that typically relieved their distress. Nevertheless, drawing on dementia time in this way

raises the question if dementia time is still liberatory if it is used to “manage” people with dementia or other mental disabilities’ “problem” behaviors.

2. **Dementia Time as a Site of Racialized, Gendered, and Classed Violence**

Furthermore, there were moments when dementia time became a site of racialized, gendered, and classed violence for the caregivers. The majority of the CNAs were Black women, either from Chicago or from various countries in Africa or the Caribbean. There were also a significant number of brown women from countries in Latin America and South Asia. Conversely, most of the old women with dementia were white women, some from wealthy backgrounds, whose ages ranged from 70 years old to over 100 years old. It is quite likely some of these women grew up with Black or brown domestic workers in their homes, cleaning their houses, and caring for their children. As Fauna, one of the old women with dementia, once told me, “I am used to Black women doing what needs to be done.” Given this historical and cultural context, the old women with dementia, particularly those from considerable privilege, would sometimes enter a situated reality in which they treated the black caregivers as “the help.” They would call out, “Ma’am?” or “Miss?” when they needed something, they would at times misgender the black women and refer to them as boys or “sir,” or they would demand the CNAs do trivial tasks that were not a part of their job description such as straightening up their rooms or fetching them items. Here is one example from my field notes when a white old woman with dementia, Eleanor, misgendered Cherise, a Black nurse who immigrated from a country in West Africa:

> *Cherise is one of the two nurses on duty. She is walking around the dining room, distributing medications to various residents. At one point, she walks by Eleanor, who calls out loudly, “Mister! Mister!” Cherise rolls her eyes. “I am a Mrs.! Not a mister!” she responds to Eleanor. “What?” Eleanor asks. “I am a Mrs.! Not a mister!” Cherise repeats firmly but gently. Eleanor stares at her and then snaps, “Go away please.” Cherise shakes her head and walks out of the dining room.*

Another Black woman, Gladys, discussed being treated as "the help" by some of the old women with dementia:

> *"[The wealthier white old women with dementia] still want to be served. They still want to be treated…as if they if they still paying like five housekeepers. Like Flora…she's [in the dementia unit] for a reason, that's why she got kicked off [the floor with the rehabilitation unit]. Because she was calling everybody 'maid' or 'sir.' Like, 'sir, go valet my car.' Or they would serve her her food, and she's like, 'You didn't tip right?' [to her husband]. 'We're not tipping that one.' She actually called me to her room, 'Maid! Maid!' I said, 'Yes, what can I do for you?' She's like, 'Maid, I need my bed made…and my pillows fluffed, I just got out of it.' I said, 'Okay.' And you know, you just do it."*

In another situation, one of the old women with dementia threatened the care workers, in addition to calling me ableist and sexist slurs.

> *Ashanti asks me to watch so she can put Sylvia in bed. Patricia keeps trying to leave, but cannot because she needs to wait for a care worker to take her to her room and help her transfer into bed. I try to convince her to stay but she becomes increasingly angry. "I am an American citizen! I have papers," she yells. "Patricia," I say, "I know this is really upsetting. I will tell the staff you want to go to your room." "You have no authority! Who the hell are you? This is just like the Nazis! I have rights!" "Patricia, you do have rights and I'm really sorry, I can certainly understand why you're upset." Patricia stares at me. "Are you crazy?" she asks. As someone with a psychiatric disability, her question is upsetting. "Yes, I am," I retort brazenly. This seems to surprise her, and she is silent for a moment but then regains her bearings and asks, "Are you stupid?" Angry with the continued ableism, I say, "Patricia, please do not talk to me like that." "You stupid little bitch!" she yells. I repeat, "Okay, Patricia, please do not talk to me this way." At this point Guadalupe enters the room and Patricia spots her and immediately yells, "I am calling the police!" Guadalupe sighs heavily but ignores her. "They are going to put you all in jail!" she yells at Guadalupe, Ashanti, and me. "You are all idiots! This is a free white country! This is a free white country!" Gloria tells Patricia, "Let me help you to your room." Patricia slaps her hand.*

Although Patricia had every right to be angry over the lack of autonomy she had and clearly the way she was being treated reminded her of oppression she had experienced as a Jewish woman, she reacted by threatening the Black and brown care workers with the violent act of calling the police and having them incarcerated. When Guadalupe tried to help her (and remove her from the situation), Patricia physically struck her. Patricia ended up going home a few weeks later, and multiple care workers told me she regularly threatened

to have them fired. The CNAs and nurses would express frustration with the racism, sexism, and classism they experienced, but they would ultimately dismiss their behavior in temporal terms, as Ciera did:

> *At [the residents'] age, this is what they were, what should I say? Accustomed to, you know? Really, when, especially with a 90, 80-year-old woman, um, Caucasian women, they got scared of Blacks and that still kind of goes on now. Or they wouldn't eat with the Blacks, they wouldn't talk with the Blacks. So that's just their mindset, especially with dementia, it's like they're kids. So, they go back to what they were taught. And I can't get mad. That's just what, you know, they were taught. So, it's better now. It's just like, it just like rolls off my shoulders. But when I first started, I wanted to quit so many times, Hailee, you don't know how many times I was called a monkey. Um, a lady told me like, oh, yeah, you can come to dinner. But you'll never leave because my brother will hang you from my oak tree.*

When I expressed horror at these racist comments and threats, Ciera again situated them in the residents' upbringing and socialization. Other care workers I spoke to about this issue made similar comments: "Oh, they grew up in a different era," or "They think they are in a time when this was normal." They reported it did not happen "too often" and they just needed to "deal with it." However, we must question what becomes of dementia time when it reifies gendered, racialized, and class oppression.

3. **Dementia Time as a Site of Distress or Trauma**

Respecting situated realities as a part of dementia time also highlights the ways in which moments may be painful, difficult, and marked by trauma. Samuels (2017) discussed the many ways in which crip time can serve as a source of loss, alienation, and grief, and the same may be true of dementia time. People with dementia and other mental disabilities may relive trauma or understand themselves to be in arduous or agonizing situations that are different from the realities of those around them. Price (2017) discussed the ways in which disabled people and people who have experienced trauma may be "together but radically not together" while with non-disabled or non-traumatized people (p. 158). In other words, they are both in, and simultaneously not in, the same space and time.

For example, given the significant number of Jewish residents in the dementia unit, there may have been residents who had trauma related to the Holocaust or World War II. One of the men living in the dementia unit, Amon, was Jewish and a World War II veteran and would occasionally begin rocking back and forth and repeating phrases such as, “The atom bomb! What atom bomb? Just lay down! No, don’t! The atom bomb!” In these types of situations, applying the tenets of dementia time becomes the most difficult. We must consider how we might move toward being radically together, even if we are in a different times and spaces. Under the tenets of dementia time, we must acknowledge the other person’s distress or trauma, while simultaneously trying to care for them, be present with them in their situated reality, and invite them to engage (or not engage) with us in whatever ways make sense for them in that moment.

H. **The Ethics of Dementia Time**

The complexities of dementia time also raise questions about the ethics of dementia time. As I engaged in dementia time, I had to navigate interactions in which applying the tenets of dementia time was not always simple or straightforward.

> *When I enter the unit, Lucille is walking toward me. I greet her, “Hi Lucille, how are you?” She signs in ASL while also speaking verbally, “Hello, I’m doing fine, thank you.” Lucille’s daughter is Deaf so she is fluent in ASL. “Oh, you’re using ASL!” I comment. Lucille says, “Well, I have to with you!” while signing. I realize Lucille believes I am her daughter. Lucille then tells me she is going to the office to see about transferring me out of this school to another school. She says there is a great school for the Deaf in St. Louis she wants to look into. I tell her I hope it works out. A few hours later, Reyna is leading an activity. Lucille keeps looking back at me and frowning and shaking her head. Reyna asks the old women with dementia how their days are going. “Nothing good happened,” Lucille announces. She looks back at me and says firmly, “I do not want my daughter here!” I realize Lucille still believes I am her daughter and my presence here is causing her distress. Reyna is confused my Lucille’s comment so simply asks, “Is your daughter your only daughter?” “Yes!” Lucille responds. “And I do not want her here!”*

In this case, I focused on the moment and acknowledged and respected Lucille’s situated reality, but it ended up later causing her distress, as she believed I was her daughter and I

was trapped in a terrible Deaf school. Unfortunately, there was not an easy way to navigate this interaction—had I not respected Lucille's reality, it may have also caused her distress. How do we approach dementia time in ways that meet the needs of people with dementia and other mental disabilities and affirm our personhood without causing harm or enacting violence? Samuels (2017) highlighted that crip time can be beautiful and forgiving as well as a site of loss and alienation—which is far more difficult to celebrate. Dementia time is also rife with challenges and complexities, but I contend that dementia time, like crip time, queer time, collective access, or other forms of liberation, requires constant reassessing and reworking, creativity, and an understanding that it is a process rather than an end goal. Approaching dementia time in this way allows us to engage in dementia time in ways that are as ethical as possible and uphold its liberatory potentiality.

I. Conclusion: Dementia Time as a Coalitional Politic

As highlighted by the theory and practice of crip time, social constructions of time, which (re)produce normative expectations of pace, scheduling, and structure, have been oppressive for disabled people. For those of us with mental disabilities, including dementia, we have also felt and experienced the ways dominant conceptualizations of time emphasize objectivity, linearity, orientation, and rationality, which further marginalizes us. Clock time and other dominant forms of time serve to uphold compulsory able-mindedness/able-bodiedness, compulsory heterosexuality, and compulsory youthfulness. Family, friends, care workers, and community members touch the lives of people with dementia and other mental disabilities in numerous ways as they work to engage in caring and supportive relationships with us. Dementia time serves as a way to (re)think interactive moments with people with dementia and other mental disabilities. By approaching time and temporality differently, we can better understand the lived experience of people with dementia and other

mental disabilities, and furthermore, engage in interactive moments that better meet all of our needs.

Moving forward, I am interested in exploring the ways dementia time can be applied in relationships, particularly relationships with people with dementia and other mental disabilities. Dementia time holds coalitional potential, as it connects those of us with diverse mental disabilities who are disabled by dominant notions and practices of time. Although dementia time is complex, it is akin to crip and queer time because it is a process and working through challenges is a way to build coalitions and community. My theory of dementia time was developed not only through interactions with people with dementia, but from my positionality as a person who has experienced trauma and is diagnosed with several psychiatric disabilities. To think about practical ways to enact dementia time, what would it mean to introduce ourselves to people every time we met? What would it mean to ask questions that do not rely one others' ability to directly connect with the past, but that focus on feelings, thoughts, and sentiments that can be experienced in the moment? What if we cued storytelling by not asking, "Remember when…" but rather requesting, "Can I talk about one of my favorite moments we shared?" What if we acknowledge and enter the realities of others without judging whether they are "true" or "objective"? By using dementia time to challenge conventional understandings of memory or rationality or rhetoricity, we can cultivate access for and relationships with people with dementia and other mental disabilities in new and exciting ways. As a person with a mental disability who has developed close and meaningful relationships with people with dementia, my desire is for dementia time to act as a way for those of us who are "out of our minds" and thus "fail to make sense" to be acknowledged, respected, and affirmed, in the present and in the future.

VII. CONCLUSION: TIME TO CARE

Institutionalized old women with dementia and care workers interact in confined spaces that are governed by overlapping and intersecting temporalities. The old women with dementia and the care workers are disciplined through time—with multiple, quantified systems measuring, evaluating, and shaping interaction. The dominant temporalities that enacted this discipline—clock time, institutional time, and bureaucratic time—create and maintain structures of care that construct time as a scarcity. However, the old women with dementia and the care workers resist these dominant temporalities. Separately and collectively, the residents and care workers find ways to spend time—a limited resource—connecting, demonstrating emotional presence, sharing meaningful moments, and caring for one another. Furthermore, old women with dementia experienced time outside of the linear, progressive, objective reality that is expected, and care workers spent time following portals into and out of "dementia time"—the spacetimes in which the old women were living in the moment. Thus, time served as a pivotal way the old women with dementia and care workers navigated relationality and power. Across all interactions in the dementia unit, time is recursively and simultaneously elastic and inflexible, in the present and in the past, and narrow and expansive.

Foucault (1998) argued that "power is everywhere" and thus cannot be located in a person or entity but rather pervades society (p. 63). Through my observations with old women with dementia and care workers, I argue that temporality is a manifestation of power, operating everywhere in the dementia unit—serving disciplinary functions as well as creating opportunity for resistance, connection, and liberation. As I conducted my fieldwork, I repeatedly found myself returning to this question: "Who has *temporal* power in the dementia unit?" The old women with dementia asserted that the care workers held the power—they could choose if the old women with dementia received assistance, what

assistance they received, and when they received it. The care workers argued that the old women with dementia had the power—they were the "consumers" of care and as a result could make demands on the care workers' time, knowing that the administration would support them should they or their families complain. It was also clear to me that the administration, and above them, the state and broader nursing home industry, had tremendous power over both the old women with dementia and the care workers, and exerted that power to create the conditions of care that simultaneously supported the survival of the old women with dementia and care workers while also isolating, marginalizing, exploiting, and dehumanizing them.

A. **Temporality as a Framework for Exploring Care Relationships**

By centering the care relationships between old women with dementia and the immigrant women of color employed to care for them in a dementia unit, my work has illuminated the importance of engaging ***temporality as a framework*** to understand the diverse ways old women with dementia and their care workers are gendered, racialized, classed, aged, and disabled within the context of the dementia unit. Researchers, policy analysts, and advocates examining time in nursing homes have typically been focused on issues such as compliance and ethics. This dissertation extends how we understand temporality in institutional spaces by centering on how time affected the lived experiences of old women with dementia and care workers and mediated their care relationships. It explored time as a form of power, and also as a site of connection, resistance, and liberation.

Temporality is a generative perspective that has received increased attention in multiple disciplines, including disability studies, aging studies, queer theory, feminist theory, and critical race theory (Altomonte, 2016; Apter, 2010; Baars, 2009; Buzzanell et al., 2017;

Coleman, 2008; Draz, 2015; Glenn, 2010; Kafer, 2013; Price, 2015, 2017). This project expands how time has been explored in disability studies, gerontology, and feminist theory in important ways. In disability studies, time has been examined as a disabling, normative social construction and as a central aspect of disability culture, a form of resistance, and a way of working toward collective access. Within gerontology, time is understood as a central aspect of human aging. Feminist theory has focused on women's time and the ways that women's time is (de)valued, disregarded, and exploited. I sought to integrate these diverse disciplinary approaches to time by reading the experiences of old women with dementia and care workers through these multiple theoretical lenses.

Furthermore, due to this interdisciplinary approach, this research filled significant gaps in the literature. Gerontology, even feminist gerontology with its focus on the body, care, and the third and fourth ages,[36] has been slow to approach temporality in the context of institutionalized women and the predominately women of color care workers who labor on their behalf. Likewise, disability studies, particularly feminist disability studies, has contributed important insights into interdependence and temporality, yet has rarely considered dementia, old age, or care workers (Erevelles, 2011; Yoshizaki-Gibbons, 2018a). Feminist theory, conversely, has often failed to consider the disabled subject in critiques of care. By employing temporality as a lens through which to view the care relationships between old women with dementia and care workers in the context of a dementia unit, this project has generated new, interdisciplinary insights into disability, aging, care, interdependence, labor, and institutionalization. In doing so, this work has advanced disability studies, gerontology, and feminist theory.

[36] The third and fourth ages are based on the idea that life has four stages, and "the third age" represents a period of "personal fulfillment" whereas "the fourth age" refers to a time of increasing dependency, debilitation, and death (Gilleard & Higgs, 2014; Twigg, 2004).

Institutionalized old women with dementia and care workers are situated in a physical space that is governed by an overlapping, conflicting, and recursive set of rules about time and time in space. Clock time, institutional time, and bureaucratic time serve as dominant temporalities within the dementia unit that create the structures of care. Clock time—or the linear progression of time as measured by clocks and calendars—served as the foundation of the dominant temporalities in the dementia unit. As clock time is quantitative, it is understood as linear, progressive, and uniform and is consequently intertwined with the neoliberal capitalist logics of economization, financialization, and accounting. Clock time underpins institutional time, which structures daily life for residents and care workers and routinizes all aspects of care, and bureaucratic time, which dictates how the nursing home operates as a business and ensures compliance with regulations of care. These dominant temporalities create and maintain a context rife with understaffing, unfair wages for workers, strict and inflexible daily routines, needing to wait to receive or provide care, and surveillance. These conditions intertwine to create an "economy of time" in the dementia unit, in which time was a scarce commodity. Consequently, the old women with dementia and the care workers had to navigate how to seek, compete for, provide, and deny time. The care dyad perpetually struggled to obtain "enough time" to have their bodily, emotional, mental, financial, and social needs met.

Despite this, the old women with dementia and care workers found ways to deny the dominant temporalities to make time for and give time to each other. The act of making time for and giving time to one another was particularly significant due to the economy of time in the dementia unit, how tightly controlled the old women with dementia and care workers' time was, and how little autonomy and self-determination they had regarding how their time was spent and structured. Making and giving time to one another represented an investment in the care relationship. Consequently, I came to understand kind yet seemingly

negligible, ordinary gestures as “gifts of time.” I argued that through these gifts of time, the care workers and old women with dementia were able to unsettle the dominant temporalities in the dementia unit and create and maintain interdependent care relationships aligned with feminist disability studies politics of relationality and time. The gifts of time allowed the care dyad to engage in shared moments of connection and collective care.

Another important site of temporality and relationship (re)building for the old women with dementia and care workers was dementia time. Dementia time, as an extension of crip time and queer time, is a temporal dis/orientation that challenges and disrupts normative and dominant forms of time. Dementia time involves focusing on a particular moment in time and space and embracing that individual moments may be self-contained, nonlinear, intermittent, irrational, and idiosyncratic, yet are no less meaningful or valuable. I forwarded four interconnected tenets of dementia time: (a) focusing on the moment; (b) maintaining rhetoricity to practice inclusion and affirm personhood; (c) acknowledging and respecting situated realities; and (d) emphasizing a politics of collectivity and care. Dementia time was not without complexities or complications—within the dementia unit, it was occasionally a site of containment and control; racialized, gendered, and classed violence; and trauma and distress. However, I contended that dementia time was akin to other forms of liberation such as crip time and collective access, and thus represented a process rather than an end goal. I then situated dementia time in feminist disability studies and crip politics by arguing that dementia time is a coalitional concept and has liberatory potential for old people with dementia and other people with mental disabilities.

B. Addressing Time, Relationality, and Power in Institutionalized Care Spaces

This project has numerous implications for the structures of care in nursing homes and how our society views and treats old people with dementia and care workers. Here, I discus the implications of this project and contend that it is "time to care" about old people with dementia and care workers in nursing homes, who need to be supported economically, socially, politically, and culturally—a need that became particularly clear in the midst of the COVID-19 pandemic.

1. Creating Just Working Conditions: Staffing, Pay, and Benefits

Cultural theorist Brittney Cooper (2017) has queried, "Who owns time?" To have ownership and control over time is to have power. As I discussed at length in Chapter IV: Dominant Temporalities in the Dementia Unit, care workers in long-term care facilities, particularly CNAs, are constantly reminded that their time is owned by the nursing home industry. Their labor is devalued in temporal terms, such as low hourly pay, limited or no benefits, changing shift schedules and work hours, requests to work longer hours, extended shifts, and double shifts due to short staffing. Their exploitation is situated in long histories of enslavement, colonization, and bonded labor (Erevelles, 2011; Glenn, 2010). Glenn (1992) observed that immigrant women of color care workers provide care so that white middle- and upper-class women are free from the "burdens" of care (Ehrenreich & Hoschchild, 2004; Guevarra, 2010). Consequently, a global supply chain has been created that provides care workers to the United States (Guevarra, 2010; McLaughlin, 2020). Within this context, marginalized women's caring work continues to be commodified and exploited. These unjust and debilitating working conditions have a significant impact on the well-being and quality of life of the care workers and residents.

Understaffing, low pay, and inadequate benefits are interconnected issues that could be addressed through policy. One major issue is that state and federal regulations define and quantify care temporally—rather than mandate a minimum number of staff per residents, they require a minimum number of hours of care per day and allow nursing homes to determine how many staff are needed to meet that minimum. Given that approximately 70% of nursing homes are private, for profit companies that are incentivized to reduce costs as much as possible in order to generate revenue, many nursing homes try to meet that hourly requirement with as few staff as possible and prioritize profits over care. Therefore, policy should establish a minimum staffing ratio (e.g., 1 CNA for every 6-8 residents). Furthermore, nursing homes should be incentivized to go beyond the minimum.

Yet another major issue is low pay and inadequate benefits. Care workers in nursing homes, particularly Certified Nursing Assistants, are significantly underpaid. Although care work requires physical, emotional, and social skills, CNAs are treated as “unskilled” laborers and are among the lowest paid workers in the United States. As previously mentioned, in 2019, the median pay for CNAs was $29,640 per year, which equates to just $14.25 per hour (U.S. Bureau of Labor Statistics, 2020). Additionally, many nursing homes, particularly for-profit facilities, provide CNAs with limited or even no benefits. Consequently, CNAs, many of whom are marginalized by gender, race, class, and immigrant status, struggle to make ends meet and provide for their families. Moreover, although home and community-based services are a more just form of care for old disabled people, as they allow them to remain in their homes and communities, HCBS, like nursing homes, still perpetuate marginalization. As Buch (2018) noted in her ethnographic study of home care programs in the Chicagoland area, home health aides are also often marginalized women who are exploited in similar ways to CNAs. In fact, many home health aides are paid even less than CNAs because their positions do not require any certifications (Paraprofessional Health

Institute, 2019). In this regard, care for old and disabled people further exacerbates social inequalities (Buch, 2018). Low pay and insufficient benefits were cited as the top reason CNAs left their jobs (McGurran, 2014). Policy must be enacted that increases the minimum wage of direct care workers to a livable wage and mandates nursing homes to provide them with benefits such as health insurance, disability insurance, vacation and sick time, family medical leave, and retirement packages.

Additionally, Medicaid daily reimbursement rates for care must be increased to support higher pay and benefits for care workers and improved living conditions for residents, such as better food, more events and activities, and single rather than double rooms (Hackmann, 2019). Neoliberal capitalism has created a context in which health and care are viewed as personal responsibilities, and despite the United States being on the precipice of a direct care worker shortage, conservatives are fighting to undo the limited progress made by the Affordable Care Act by reducing Medicaid reimbursement rates and capping the amount states can spend on people covered by Medicaid (Oh, 2017). Increasing the Medicaid daily reimbursement rates—and requiring that the majority or all of the increase go toward labor equity and improving quality of care—will support mandates of increased pay and improved benefits for care workers and enhance nursing home residents' lives.

2. **Reimagining and Reforming (Institutional) Care**

Nursing homes are complex spaces—they are simultaneously homes and medical centers, social service providers and businesses, and sites of care and confinement. Although numerous efforts have been made to improve and reform nursing homes, a significant number of nursing homes still prioritize profits over people and provide substandard care (U.S. Department of Justice, 2020). While both disability studies and

gerontology prioritize community care for old and disabled people, disability studies approaches institutionalization from an abolitionist perspective (Ben-Moshe, 2020; Chapman et al., 2014), whereas gerontologists consider ways to improve institutions should elders need to enter them (Beerens et al., 2013). This distinction creates tensions in considering interdisciplinary approaches to revolutionizing care.

Should nursing homes be reformed or should they be eliminated in favor of home and community-based services or alternative models of care? Can care even be improved in a context of confinement, exploitation, isolation, violence, and profiteering? If nursing homes were eradicated, are there sufficient home and community-based services in place to support the needs of old disabled people, including people with dementia? These are all difficult, complex questions to answer.

a. **Well Past Time: Working Toward Deinstitutionalization**

Unfortunately, old people with dementia have been largely left out of disability rights and justice movements, including movements to deinstitutionalize. Furthermore, deinstitutionalization efforts have primarily focused on young and middle-aged disabled people, often based on the assumption that these disabled people do not “belong” in “old folks’ homes.” Thus, the disability community must consider ways to include elders and other marginalized groups who may have complex personal care needs and may not identify as disabled but are subject to ableism in the confines of nursing homes and other institutional spaces (Lewis, 2020).

Deinstitutionalization for old people with dementia is particularly complicated because American society does not currently have adequate structures in place to care for

every person with dementia in the community.[37] Informal caregivers are already providing an extensive amount of unpaid care to old and disabled family members, friends, and neighbors—often without proper financial, emotional, and social supports. This unpaid labor often exacerbates inequalities of gender and class, as most informal caregivers are women and caregiving can have detrimental effects on their ability to work and earn income (Alzheimer's Association, 2020a). In 2017, it was estimated that informal caregivers provided approximately 34 billion hours of unpaid care which equated to an economic value of $470 billion dollars (Reinhard et al., 2019). Many of the old women with dementia in Cedarwood Care Center had previously been cared for in the community by informal caregivers but were placed in the nursing home when the informal caregivers felt they could no longer meet their needs and ensure their safety. For example, Mischa's family had tried to care for her on their own, and when that no longer became sustainable, they hired 24-hour home care. However, they shared that they felt they needed to place her in Cedarwood Care Center after she started awakening and wandering five to six times per night. Many of the old women's relatives felt they had exhausted all their options prior to placing their family member in a nursing home. Thus, policy is needed to establish greater financial, social, and emotional supports for informal caregivers and caregivers need access to care coordinators who can guide them in accessing more community resources.

Additionally, home and community-based services are currently too limited to support deinstitutionalization of nursing homes. Funding for home and community-based services needs to be increased to support all old and disabled people living in the community. Funding increases also must be accompanied by programs that specifically

[37] To be clear, I am not arguing against caring for old disabled people with dementia in the community. I am, however, emphasizing the many structural changes that are needed before our society can achieve the goal of fully deinstitutionalizing nursing homes.

cater to the needs of old people with dementia. Many of the old women with dementia required 24-hour care and some states, including Illinois, do not offer 24-hour care through their HCBS programs. For example, under Illinois' HCBS Waiver for the Elderly, individuals are eligible for adult day services, homemaker services, and an emergency home response system—but not 24-hour care (Illinois Department of Healthcare and Family Services, n.d.). Some states, such as Massachusetts and Virginia, have implemented HCBS waivers for people with dementia and Massachusetts' program specifically aims to prevent people with dementia from being institutionalized in long-term care facilities (Garfield et al., 2015). Furthermore, in Illinois and throughout the United States, there are currently long wait lists for HCBS waivers (Dernbach, 2019). Policies must be enacted that significantly increase funding for Medicaid and HCBS, create waiver services and programs that specifically meet the needs of people with dementia, and decrease or eliminate waiting HCBS waiting lists.

Yet another challenge of home and community-based services is ensuring that people with dementia who receive care in the community are included and able to participate in society in ways that are meaningful to them. Cummins and Lau (2003) emphasized that there is a significant difference between physical integration and social integration into the community, and "some disabled people find effective social integration with the general community extremely difficult to achieve" (p. 145). Within the dementia unit, the residents formed diverse and important relationships with each other, and connected in ways that people without dementia might struggle to understand or enact. These types of relationships, in addition to relationships within the broader community, must be supported when transitioning old people with dementia to home and community-based services.

Returning to Ben-Moshe's (2020) call for abolition and Kim's (2017) crip of color critique, there are ways to envision care outside of the realm of the State. Kim (2017) elucidated that a crip of color critique seeks to understand and establish "relations of social,

material, and prosthetic support—that is, the various means through which lives are enriched, enabled, and made possible. In doing so, it honors vulnerability, disability, and interdependence" (para 3). For instance, as highlighted by Akemi Nishida (2020), disabled communities have imagined radical futures in which care collectives meet the needs of disabled people, thereby protecting them from State control, surveillance, and violence. What might it look like to include old people with dementia in such collectives? How might we build on the work of dementia villages or intentional communities that seek to care for old disabled people, including people with dementia, outside of institutions (Planos, 2014)? Exploring such questions is an important part of dreaming and enacting radical imaginaries of community care.

As a society, we must imagine—and invest in—community care that meets the needs of all old and disabled people without exploiting informal caregivers and formal care workers. Care should not be a site of profit, exploitation, marginalization, or confinement, but rather understood as a human experience, a collective responsibility, and a primary way we practice interdependence. As noted by Glenn (2010), we must work toward a society in which caring is recognized as "real work" and valued socially, culturally, and economically and in which old and disabled people are respected, included, and able to participate in all aspects of society.

b. **In the Meantime: Improving Care in Nursing Homes**

As we work toward deinstitutionalization, it is still worth considering how to improve care in nursing homes, as nearly 5 million old and disabled people currently inhabit these spaces of care and confinement. To start, creating more just working conditions for care workers, as previously discussed, will improve care in institutional contexts, as old people with dementia will be able to receive more personalized time and

attention with increased numbers of staff. Relatedly, the care workers are the experts on direct care and should be treated as such. The CNAs repeatedly told me they felt that no one listened to them or respected them—in the nursing home or in society in general. However, many of the CNAs had numerous ideas about how to improve care at Cedarwood Care Center. For example, in my interview with Gladys, I asked her if she had thoughts about how to improve care in the dementia unit and she immediately fired off a number of ideas that would address many of the issues discussed throughout this project:

> *It'd be a one [CNA] to six residents ratio. There'd be three nurses on the units. One manager per floor. Mealtimes would be stretched. And then, the dementia unit would have more activities targeted towards smaller groups. So instead of having 40 people on one wing, you'd have, you would have ten, ten, ten and ten people on each wing. So those groups would be…the focus would be on people who are more similar to each other. So, if it was more so nonverbal people, you'd have more cueing activities. If it was people who are verbal, you'd have more vocal activities. If it were people like Sylvia or Nadine, you'd have more like scented activities and sensory activities. Like, you can do those things, if you had more staff, and dividing the [people with dementia] into small groups, they would have less confusion and be more involved and engaged as well.*

The nursing home industry could substantially improve care by centering the perspectives of the care workers and other "invisible" workers in the nursing home, including dining services, maintenance, laundry, and housekeeping workers.

Likewise, the old women with dementia are also experts on their own care and their needs and desires should also be respected. Cedarwood Care Center did have a Resident's Council, which is a committee of nursing home residents who meet to discuss issues and propose possible solutions. However, none of the residents with dementia were on the Resident's Council, nor was there a Resident's Council specific to the dementia unit. Doing so would ensure that dementia care was designed and implemented using the disability rights mantra of "nothing about us without us."

Furthermore, policy needs to better support the implementation of person-centered care. Person-centered care is too often understood as a requirement nursing homes must

meet and a paper pushing exercise to demonstrate to the state they met those requirements, rather than a philosophy and approach to care that centers old disabled people and respects their preferences and desires. Addressing issues of understaffing and creating a more flexible institutional routine will allow more time for person-centered care. Other ways to support person-centered care include providing additional training for administrators and care workers on what person-centered care means and how it might be implemented in diverse contexts, creating and sustaining organizational policies and practices that support person-centered care, and educating administrators and care workers on disability studies perspectives that might eliminate stereotypical attitudes toward people with dementia or other mental disabilities.

Relatedly, the old women with dementia and the care workers should be provided with more autonomy and self-determination over how their time is spent and how they structure their care relationships. Care workers should be able to decide how and when they spend their time engaging in care tasks and they should have enough time to provide more personalized and humanizing care to the residents. The institutional routine should be more flexible to account for people's preferences and the dynamic nature of care. For example, residents should be able to eat meals when they prefer, rather than during a set hour. Furthermore, residents with dementia should not be subject to boredom and monotony and treated as if they are simply "waiting to die." Residents should have more freedom to pursue their personal interests and hobbies as well as more opportunities to participate in small group activities that are catered to their capacities and accommodate them appropriately.

The Nursing Home Reform Act of 1987 (OBRA 42 CFR 483.30) created a Residents' Bill of Rights which includes:

1. The right to live in a caring environment free from abuse, mistreatment and neglect;

2. The right to live without the fear of enduring physical restraint;
3. The right to privacy;
4. The right to receive personal care that accommodates physical, medical, emotional and social needs;
5. The right to a social contact/interaction with fellow residents and family members;
6. The right to be treated with dignity;
7. The right to exercise self-determination;
8. The right to exercise freedom of speech and communicate freely;
9. The right to participate in the creation and review of one's individualized care plan;
10. The right to be fully informed in advance of any changes to care plan or status of the nursing home; and
11. The right to voice grievances without discrimination or reprisal.

However, this bill of rights is written broadly and not specific to people with dementia. A supplemental bill of rights should exist that considers how to ensure people with dementia are able to access these rights in meaningful ways. For example, nursing homes should have plans that outline how people with dementia will be included in decision-making processes about their individual care plans, their end of life wishes, and their everyday lives (Fetherstonhaugh et al., 2013). Nursing homes could learn a great deal from self-advocates and people who work with those with intellectual and developmental disabilities about supported decision-making and how to ensure decision-making is as accessible as possible to old people with dementia and other mental disabilities.

Regulation of nursing homes is another key area of nursing home care that must be addressed. The Obama Administration implemented a series of rules aimed at improving the treatment of residents, increasing standards of care, and preventing the spread of infections and contagious diseases. Furthermore, the rules also strengthened the original residents' bill of rights and imposed significantly higher fines and penalties for nursing homes found to be in violation of any rules and regulations (Cokley & Novak, 2020). The nursing home lobby fought hard against these changes, and the Trump Administration elected to deregulate and reverse or ease the requirements of the rules and regulations—including those related to the prevention of infection.

3. Care in the Time of Pandemic: COVID-19 and Beyond

In times of national crisis, old and disabled people are devalued and are often subject to debilitation and even death. For example, in the midst of Hurricane Katrina, old and disabled people were—literally—left behind to die (Barry & Miller, 2005). Many emergency, contingency, and evacuation plans do not take into account the needs of old and disabled people, and inequalities within society that oppress old and disabled people become heightened during emergencies (Otte, 2015). Such disparities have become particularly clear in the midst of COVID-19, as nursing homes are ground zero for the pandemic.

Many of the implications previously discussed are directly relevant in the COVID-19 crisis. The continued prevalence of congregate care for old disabled people in the United States—in addition to issues such as deregulation, overcrowding, understaffing, and lack of PPE—has led to a significant number of infections and deaths among nursing home residents and care workers. Recently, disabled activist Reid Knight (2020) argued that COVID-19 demonstrates how essential it is to close institutions down in favor of home and community-based services. Additionally, the need for fair wages and benefits has also become crystallized in the context of the COVID-19 pandemic. Despite representing the largest category of healthcare workers in the United States, CNAs and other direct care workers have received little support in the midst of the pandemic. Their hourly wages have remained low, and many have been denied benefits such as hazard pay and paid time off if they fall ill or if their family members fall ill (Gerety, 2020). On top of that, many have been denied access to PPE, including masks, due to a shortage of medical supplies. Under the current circumstances, direct care workers are particularly at risk for contracting and circulating COVID-19 because they do not have proper protection and support, and due to

low wages, many work second or even third jobs, and many have families for whom they also care.

Furthermore, the COVID-19 pandemic highlights why nursing home regulation is so important. The series of deregulations under the Trump Administration are one of the primary reasons COVID-19 has spread through nursing homes like “wildlife” (Cokley & Novak, 2020). Moreover, as a result of this deregulations, there have been reports of old and disabled people in nursing homes being experimented on without their consent to test hydroxychloroquine as a possible treatment for COVID-19 and nursing home lobbyists are seeking further deregulation by advocating to limit residents’’ and families’ options for legal recourse if residents are exposed to, contract, or die from COVID-19 (Cokely & Novak, 2020; Romo, 2020). Moving forward, until deinstitutionalization can be achieved, nursing home care must be reimagined in ways that center the rights, needs, desires, safety, and health of residents, their families, and care workers—rather than the interests and profits of the nursing home lobbyists or wider nursing home industry.

C. **Future Directions**

This project laid the groundwork for numerous theoretical possibilities that could be explored in future scholarship. In this section, I ruminate on some of the possibilities, organized around the primary takeaways of this research.

1. **Dominant Temporalities and Economies of Time**

First, one of the major findings of this study was that time has disciplinary power through the dominant temporalities of clock time, institutional time, and bureaucratic time. Furthermore, these dominant temporalities interwove to create an economy of time in the dementia unit. These insights raise the questions:

- How is the disciplinary power of time site-specific? How do economies of time operate in other settings? What is unique about how dominant temporalities operate in nursing homes?
- How does temporal power or economies of time manifest in other sites of care, such as families and home and community-based care?
- How do they manifest in other sites of confinement, such as prisons, immigrant detention centers, psychiatric units, and group homes?
- How does feminist work on care and women's work relate to these dominant temporalities and the economy of time?
- How does time as a disciplining power interact with disability, age, race, gender, class, and immigrant status?

2. **Making Time, Giving Time, and Gifts of Time**

Yet another key insight was the ways the old women with dementia and care workers resisted the dominant temporalities by making time for and giving time to each other, as gifts of time. Potential questions to consider include:

- How are gifts of time present in other spaces of care and confinement?
- How does making time for and giving time to each other connect to crip politics in other contexts?
- How is giving and making time relevant to other conversations about interdependence or disability feminist ethics of care?
- How is giving and making time relevant to power and resistance? When power is unequal? How are these gifts of time non-equivalent given positionality and social identities of disability, age, gender, race, class, and immigrant status?

3. **Dementia Time**

A third major discovery was how the care workers and old women with dementia (re)built relationships through dementia time, a temporal dis/orientation that allowed them to focus on a particular moment in time and place and enter situated realities with one another. Explorations about dementia time might examine:

- What might applying the tenets of dementia time look like in other spaces? How might applications differ depending on context?
- What other tenets of dementia time might we uncover through interactive moments with people with dementia or other mental disabilities?
- In what ways might we unlock dementia time's coalitional potential?
- How does the concept of dementia time relate to theoretical conversations about autonomy, relationality, and personhood, such as Martha Nussbaum's (2011) capabilities approach or Eva Feder Kittay's discussions of dependency and interdependency?
- What are the theoretical, policy, and applied implications of dementia time?

Given the interdisciplinary nature of this project, there are numerous possibilities for future work that would further theoretical explorations of time, power, relationality, and care. These questions also position disability, aging, and feminist theory to center care relationships—rather than either side of the care dyad—in their considerations of care and analyze how age, disability, gender, race, class, and immigrant status influence the experiences and structures of care. Additionally, several of these provocations prompt disability, aging, and feminist studies to include old women with dementia and immigrant women of color care workers in subsequent research on care, temporality, interdependence, relationality, institutionalization, and confinement.

D. **To Everything There is a Season**

As I pondered how to end this dissertation, a project into which I poured so much thought, energy, heart, and (no pun intended) time, I learned that one of my participants, Sylvia, had died. Sylvia was one of the old women with dementia I felt closest to throughout my research—perhaps because I spent a great deal of time caring for her, perhaps because, like Sylvia, I too have diagnoses of "severe and persistent mental illness," and perhaps because Sylvia consistently showed me so much care, support, and love throughout my research. Leading up to my last day of fieldwork, I had been crying for weeks. It was heartbreaking to leave the old women with dementia and care workers, whom I spent so much time with over the course of nine months. I am not sure what possessed me to do this, but I decided to record my goodbye to Sylvia. I think it was because right in the middle of my fieldwork, I lost my dad to colon cancer. My dad had been placed in hospice before he died, which had provided me with time to reflect on our complicated relationship and think about how I wanted to say goodbye to him. After his death, I continued to think about goodbyes—what they mean and how often in our society we deflect and avoid them. So, when it was time to say goodbye to Sylvia, I approached it intentionally and wanted it to be memorialized in some way—as a special and significant moment in time. When I learned of her death, I listened to the recording for the first time in almost a year.

> *Hailee: Sylvia, I'm going to miss you.*
> *Sylvia: Yes.*
> *Hailee: I'm going to miss you a lot.*
> *Sylvia: Oh, me too!*
> *Hailee: I love you.*
> *Sylvia: I do too. [A huge smile spreads over Sylvia's face.]*
> *Hailee: I like your big smile.*
> *[Sylvia laughs and presents her cheek for me to kiss, and I oblige.]*
> *Sylvia: That's good, that's one. I was glad!*

At the start of this dissertation, I noted that Sylvia's life as an institutionalized old woman with dementia was, in many ways, defined by time. Her death, which occurred in the midst of the COVID-19 pandemic, when no one could be there to be by her side, was defined by time too. Yet the time we spent together is preserved—in this recording, in my field notes, and in this project. May her memory be a blessing.[38]

[38] Among Jewish people, this statement is offered to comfort mourners and to honor the person who died.

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APPENDIX

A. IRB Approval Letter

Approval Notice
Initial Review (Response To Modifications)

April 30, 2018

Hailee Gibbons, MS
Disability and Human Development
Phone: (614) 330-1039

RE: **Protocol # 2018-0394**
"Care Relationships between Old Women with Dementia and Nursing Home Staff"

Dear Ms. Gibbons:

Effective April 16, 2018, OPRS has implemented a new Continuing Review policy that allows an extended approval period of three (3) years for research meeting specific criteria. The IRB has determined that this protocol is eligible for the extended approval period. Please refer to the OPRS policy for additional information: http://research.uic.edu/node/735

Your Initial Review (Response To Modifications) was reviewed and approved by the Expedited review process on April 29, 2018. You may now begin your research

Please note the following information about your approved research protocol:

Protocol Approval Period: April 29, 2018 - April 28, 2021
Approved Subject Enrollment #: 20
Additional Determinations for Research Involving Minors: These determinations have not been made for this study since it has not been approved for enrollment of minors.
Performance Sites: CJE SeniorLife (Lieberman Center Health and Rehabilitation), UIC
Sponsor: None
PAF#: Not applicable
Research Protocol(s):

a) Care Relationships between Old Women with Dementia and Nursing Home Staff (Initial Review Application);04/13/2018

Recruitment Material(s):

a) Information Letter for Staff; Version 2; 04/13/2018
b) Study Information Letter for Residents' LARs; Version 2; 04/13/2018
c) Eligibility Screener for Staff; Version 1; 04/13/2018

d) Eligibility Screener for Residents; Version 1; 04/13/2018
e) Follow Up Script - Resident LARs; Version 1; 04/19/2018
f) Follow Up Script - Staff; Version 1; 04/19/2018
g) LAR Contract Script; Version 2; 04/30/2018

Informed Consent(s):

a) Informal Interview Assent Script; Version 1; 04/11/2018
b) Informed Consent for LARs; Version 2; 04/19/2018
c) Informed Consent for Staff; Version 2; 04/19/2018
d) A waiver of documentation of informed consent has been granted under 45 CFR 46.117 and an alteration of consent has been granted under 45 CFR 46.116(d) for the informal interviews;(minimal risk; verbal consent to will be obtained.
e) Waiver of informed consent/assent/permission granted [45 CFR 46.116(d)] for the identification of potential subjects in the recruitment phase of the research; minimal risk.
f) A waiver of documentation of informed consent has been granted under 45 CFR 46.117 and an alteration of consent has been granted under 45 CFR 46.116(d) for recruitment purposes only; minimal risk; verbal consent to screening/eligibility questions will be obtained; written consent/permission and verbal assent will be obtained at enrollment.
g) A waiver of informed consent/assent/permission has been granted under 45 CFR 46.116(d) for observations (no identifier will be recorded) purposes only; minimal risk.

Assent(s):

a) Assent Script; Version 2; 04/13/2018

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific category(ies):

(5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis)., (6) Collection of data from voice, video, digital, or image recordings made for research purposes., (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
03/27/2018	Initial Review	Expedited	04/03/2018	Modifications Required

04/20/2018	Response To Modifications	Expedited	04/29/2018	Approved

Please remember to:

→ Use your **research protocol number** (2018-0394) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the OPRS website at,
"**UIC Investigator Responsibilities, Protection of Human Research Subjects**"
(*http://tigger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf*)

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 355-0816.

Sincerely,

Alison Santiago, MSW, MJ
Assistant Director, IRB # 2
Office for the Protection of Research Subjects

Enclosure(s) are accessible via OPRS Live:

1. **Informed Consent Document(s):**
   a) Informal Interview Assent Script; Version 1; 04/11/2018
   b) Informed Consent for Staff; Version 2; 04/19/2018
   c) Informed Consent for LARs; Version 2; 04/19/2018
2. **Assent Document(s):**
   a) Assent Script; Version 2; 04/13/2018
3. **Recruiting Material(s):**
   a) Information Letter for Staff; Version 2; 04/13/2018
   b) Study Information Letter for Residents' LARs; Version 2; 04/13/2018
   c) Eligibility Screener for Staff; Version 1; 04/13/2018
   d) Eligibility Screener for Residents; Version 1; 04/13/2018
   e) Follow Up Script - Resident LARs; Version 1; 04/19/2018
   f) Follow Up Script - Staff; Version 1; 04/19/2018
   g) LAR Contract Script; Version 2; 04/30/2018

cc: Tamar Heller, Disability and Human Development, M/C 626
Tamar Heller (Faculty Advisor)

VITA

HAILEE YOSHIZAKI-GIBBONS*

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EDUCATION

Doctor of Philosophy	University of Illinois at Chicago: Chicago, IL Disability Studies *Concentration*: Gender and Women's Studies University Fellow and Dean's Scholar Fellow *Dissertation*: Time and Again: Old Women and Care Workers Navigating Time, Relationality, and Power *Advisor*: Dr. Tamar Heller *Committee*: Dr. Carrie Sandahl, Dr. Brian Grossman, Dr. Beth Richie, & Dr. Jennifer Kinney	August 2020
Master of Science	Miami University: Oxford, OH Student Affairs in Higher Education *Concentration*: Inquiry in Education	May 2013
Bachelor of Philosophy	Miami University, Oxford OH Interdisciplinary Studies *Concentration*: Gerontology, Psychology, and Family Studies *Thesis*: Linking Lives: Improving Intergenerational Relations through Service-Learning	May 2008

CERTIFICATIONS

Certificate in Online Teaching	Concordia University, River Forest, IL.	February 2014
Certificate in College Teaching	Miami University: Oxford, OH	May 2013

TEACHING EXPERIENCE

University of Illinois at Chicago: Chicago, IL

COURSES DEVELOPED AND TAUGHT

Disability and Human Development Capstone	Instructor	Fall 2015-Spring 2018

COURSES TAUGHT

Gender in Everyday Life	Co-Instructor	Fall 2019-Spring 2020
Disability Rights and Culture	Co-Instructor	Spring 2016, Spring 2017

TEACHING ASSISTANT EXPERIENCE

Disability in American Film	Teaching Assistant	Fall 2014, 2015
Disability in American Film [Online]	Teaching Assistant	Summer 2015, 2016
Disability Rights and Culture	Teaching Assistant	Spring 2015

Miami University: Oxford, OH

COURSES TAUGHT

Service-Learning: Theory into Action	Co-Instructor	Spring 2013

COURSES DEVELOPED AND TAUGHT

Intersections of Race, Class, and Education	Instructor	Spring 2012
Adopt A School Honors Experience	Instructor	Fall 2009- Spring 2011
Issues in Education	Instructor	Spring 2010
Community Engagement and Service-Learning	Instructor	Fall 2009- Spring 2011

COURSES REDESIGNED AND TAUGHT

Media Illusions of Disability	Co-Instructor	Spring 2013
EMPOWER: Introduction to Social Justice	Instructor	Fall 2011-Fall 2012

TEACHING ASSISTANT EXPERIENCE

Introduction to Disability Studies	Teaching Assistant	Spring 2012
Aging in American Society	Teaching Assistant	Spring 2008
Women & Theatre: Politics of Representation	Teaching Assistant	Spring 2006

PUBLICATIONS

REFEREED ARTICLES

Heller, T., Esbensen, A., Fazio, S., **Yoshiaki-Gibbons, H. M.**, Hartley, D. H., Janicki, M. … Wheeler, B. (2018). Caregiving, intellectual disability, and dementia: Report of the Summit Workgroup on Caregiving and Intellectual and Developmental Disabilities. *Alzheimer's & Dementia: Translational Research & Clinical Interventions, 4,* 272-282.

Dunford, C. M., **Yoshizaki-Gibbons, H. M.**, Morhardt, D. J. (2017). The memory ensemble: Improvising connections between performance, disability, and aging. *Research in Drama Education: The Journal of Applied Theatre and Performance, 3*(22), 420-426.

Heller, T., Owen, R., Bowers, A., & **Gibbons, H. M**. (2017). Aging with a physical disability in Medicaid Managed Care. *Research on Aging, 39*(6).

Gibbons, H. M. (2016). Compulsory youthfulness: Intersections of ableism and ageism in "successful aging" discourses. *Review of Disability Studies, 12*(2&3), 70-88.

Gibbons, H. M., & Gibbons, C. M. (2016). Siblings with disabilities: A duoethnography on the intersections between a sibling relationship and disability. *Disability & Society, 31*(6), 820-837.

Gibbons, H. M., Owen, R., & Heller, T. (2016). Perceptions of health and healthcare of people with intellectual and developmental disabilities enrolled in Medicaid Managed Care. *Intellectual and Developmental Disabilities, 45*(2), 95-105.

Heller, T., **Gibbons, H. M.**, & Fisher, D. (2015). Caregiving and family support interventions: Crossing networks of aging and developmental disabilities. *Intellectual and Developmental Disabilities, 53*(5), 329-345.

Radina, M. E, **Gibbons, H. M.**, & Lim, J. (2009). Explicit versus implicit family decision-making strategies among Mexican- American caregiving adult children. *Marriage & Family Review, 45*(4), 392 - 411.

Radina, M. E., Hennon, C. B., & **Gibbons, H. M.** (2008). Divorce and mid- and later life families: A phenomenological analysis with implications for family life educators. *Journal of Divorce & Remarriage, 49*(1/2), 142 - 170.

BOOK CHAPTERS

Yoshizaki-Gibbons, H. M. (2018.) Engaging with aging: The "greying" of critical disability studies. In R. Garland-Thomson, K. Ellis, M. Kent, & R. Robertson (Eds.), *Manifestos for the Future of Critical Disability Studies* (pp. 179-188). New York, NY: Routledge.

Yoshizaki-Gibbons, H. M., & O'Leary, M. E. (2018.) Deviant sexuality: The hypersexualization of women with bipolar disorder in film and television. In J. Leeson-Schatz & A. George (Eds.), *The Image of Disability: Essays on Media Representations* (pp. 93-106). Jefferson, NC: McFarland.

Yoshizaki-Gibbons, H.M. (2018). Critical disability studies. In T. Heller, S. Parker Harris, C. Gill, & R. P. Gould (Eds.), *Disability in American Life: An Encyclopedia of Concepts, Policies, and Controversies* (pp. 149-152). Santa Barbara, CA: ABC-CLIO.

INVITED PUBLICATIONS

Yoshizaki-Gibbons, H. M. (In Press.) Intersections of critical gerontology and critical disability studies. In M. Putnam & C. Bigby (Eds.), *Handbook of Aging with Disability.* New York, NY: Routledge.

IN PROGRESS PUBLICATIONS

REFEREED ARTICLES

Yoshizaki-Gibbons, H. M. (In Progress.) The (im)persistence of memory: Crip time and the politics of dementia. *Scandinavian Journal of Disability Research.*

Yoshizaki-Gibbons, H. M. (In Progress). Challenging the never-ending funeral: Reinterpreting dementia through a disability studies lens.

EDITORIAL EXPERIENCE

Content Editor, *Disability in American Life: An Encyclopedia of Concepts, Policies, and Controversies.* Editors: T. Heller, S. Parker Harris, C. Gill, & R. P. Gould. Santa Barbara, CA: ABC-CLIO.

HONORS & AWARDS

2018-2019	**Dean's Scholar Fellowship** University of Illinois at Chicago
2018-2019	**Ann and Edward Page-El Scholarship for Research on Social Aspects of Neurological Disabilities** Disability and Human Development, University of Illinois at Chicago
2013-2018	**University Fellowship** University of Illinois at Chicago
2017-2018	**Charlotte A. Tate Award for Multidisciplinary Research** Disability and Human Development, University of Illinois at Chicago
2017-2018	**Alice J. Dan Dissertation Award** Center for Research on Women and Gender, University of Illinois at Chicago
2017-2018	**Marian K. Hume Memorial Endowed Scholar Award** P.E.O. Sisterhood
2017-2018	**P.E.O. Scholar Award** P.E.O. Sisterhood

2016 **Excellence in Undergraduate Mentoring Award**
Graduate College & Honors College, University of Illinois at Chicago
2016 **Chancellor's Student Service and Leadership Award**
University of Illinois at Chicago
2015 **Kate Welling Disability Studies Lecture Series Emerging Scholar**
Miami University
2015 **Anne Hopkins Scholarship Award**
University of Illinois at Chicago
2013 **Social Justice Studies Service Award**
Department of Sociology & Gerontology, Miami University
2012 **Graduate Student Women's Leadership Award**
Women's Center, Miami University
2011 **Videographer Award**
Association for Marketing and Communication Professionals
Received for the Video "Faculty Orientation for Service-Learning"
2011 **Outstanding Supervisor Award**
Office of Community Engagement and Service, Miami University
2010 **Project Search Star Supporter Award**
Butler County Board of Developmental Disabilities, Oxford, Ohio
2008 **President's Distinguished Service Award**
Miami University
2008 **Senior Service Award**
Miami University
2008 **Gerontology Leadership Award**
Department of Sociology & Gerontology, Miami University
2007 **Charles J. Ping Award for Outstanding Leadership & Contribution to Community Service**
Ohio Campus Compact

TRAVEL GRANTS

2017 **CCCC Disability in College Composition Travel Award**
National Council of Teachers of English
2016 **President's Diversity in Research Travel Award**
University of Illinois
2015 **NWSA Travel Grant**
National Women's Studies Association
2014 **Emerging Scholar Travel Award**
Accelerating Translation of Knowledge to Community Practices in Aging with a Disability
Gerontological Society of America
National Center on Gerontological Social Work Excellence

PRESENTATIONS

Abustan, P., Acevedo, S., Hou, L., Pearson, H., & **Yoshizaki-Gibbons, H.M.** (2020). Narrating disability at the intersections: Peripheral embodiments and the power of interwoven storytelling. Presented at Society for Disability Studies Conference. Columbus, OH.

Yoshizaki-Gibbons, H. M. (2019). Conducting feminist research in the context of care and confinement. Panel presentation: Feminist Research with Multiply Marginalized Communities: Expanding Feminist Methodological Possibilities. Presented at the National Women's Studies Association Conference. San Francisco, CA.

Aho, T., **Yoshizaki-Gibbons, H. M.**, Cartwright, L. E., O'Leary, M. E., Wang, J. & Whatcott, J. (2019). Mad time/s of/and Anxiety, Chronic Illness, Neuroqueerness: Incarcerating Realities, Imagine-Building Futures. Presented at the National Women's Studies Association Conference. San Francisco, CA.

Yoshizaki-Gibbons, H. M. (2019). "There's nowhere to go": The complexities of interdependence in dementia units of American nursing homes. Panel presentation: Interdependence, commodified: (Re)examining power and care. Presented at the Society for Disability Studies Conference. Columbus, OH.

Yoshizaki-Gibbons, H. M. (2018). (Re)humanizing old women with dementia: Constructing time and space as demented. Presented at the National Women's Studies Association Annual Conference. Atlanta, GA.

Carter, A. M., **Yoshizaki-Gibbons, H. M.**, Aho, T., Horvath Williams, & J., Schmitt, S. R. (2018). Visions of institutional justice: Dream making the futurescapes of disability studies. Presented at the National Women's Studies Association Annual Conference. Atlanta, GA.

Yoshizaki-Gibbons, H. M. (2018). Dementia as debility: Integrating disability, aging, and feminist perspectives. Presented at the Chicago Disability Studies Conference. Chicago, IL.

Yoshizaki-Gibbons, H. M. (2018). Exploring intersections of aging and disability through the "greying" of disability studies. Presented at the Multiple Perspectives on Access, Inclusion, and Disability Conference. Columbus, OH.

Yoshizaki-Gibbons, H. M. (2018). Co-constructions of aging, disability, and time in the context of care and confinement. Panel presentation: Thinking in/Through timescapes and disability: Composing divergent experiences of time. Presented at the Conference on College Composition and Communication. Kansas City, MO.

Yoshizaki-Gibbons, H. M. (2017). Kept out or kept in: The evolution of nursing homes into racialized and class-based spaces of confinement for disabled elders. Panel presentation: Disability and state violence. Presented at the National Association of Women's Studies Conference. Baltimore, MD.

Yoshizaki-Gibbons, H. M. (2017). Beyond the social model: Exploring dementia as debility in disability studies. Panel presentation: Vulnerability/debility/disability: Theorizing/finding new forms of dissent. Presented at the American Studies Association Annual Conference. Chicago, IL.

Yoshizaki-Gibbons, H. M. (2017). Nursing homes as sites of carceral violence for disabled elders. Presented at the Chicago Disability Studies Conference. Chicago, IL.

Heller, T., Owen, R., Bowers, A., **Yoshizaki-Gibbons, H. M.**, Yamaki, K., & Crabb, C. (2017). Aging with a physical disability in Medicaid Managed Care. Presented at the IAGG World Congress of Gerontology and Geriatrics. San Francisco, CA.

Broyer, n. R. & **Yoshizaki-Gibbons, H. M.** (2017). "The Ramp Is for Wheelchairs Only!": Disability, Public Transportation, and the Politics of (In)Visibility. Presented at the Chicago Ethnography Conference. Chicago, IL.

Yoshizaki-Gibbons, H. M. (2017). Using "demented time" to cultivate access and relationships with people with mental disabilities. Panel presentation: The nonrational/nonspeaking subject: A disability studies analysis through narrative,

qualitative research, and philosophical inquiry. Presented at the Conference on College Composition and Communication. Portland, OR.

Yoshizaki-Gibbons, H. M. (2017). The (im)persistence of memory: Crip time and the politics of dementia. Presented at The Aging/Disability Nexus Workshop. Toronto, ON.

Gibbons, H. M. (2016). Redefining successful aging in adults with lifelong disabilities. Panel presentation: Aging with lifelong disability: Theoretical perspectives. Presented at the Annual Meeting of the Gerontological Society of America. New Orleans, LA.

Eisenstein, A., Berman, R., Johnson, R. **Gibbons, H. M.**, Houpt, K., Voloschin, P., Koch, A., & LaCroix, A. (2016). The bureau of sages: Changing attitudes in research. Presented at the Annual Meeting of the Gerontological Society of America. New Orleans, LA.

Gibbons, H. M. (2016). Compulsory youthfulness in a time of dementia: Unsettling the ideal of able-mindedness in later life. Panel presentation: Resisting Settler Logics in Notions of Compulsory Able-Mindedness and the Mad Subject. Presented at the National Women's Studies Association Annual Conference. Quebec, Canada.

Gibbons, H. M. (2016). Using crip time and demented time to transform interactive moments with people with dementia. Presented at the Applied Disability Studies Symposium. Minneapolis, MN.

Gibbons, H. M. (2016). The increase in Latinx elders in nursing homes and the need to expand deinstitutionalization efforts to include older adults of color. Presented at the National Conference for Latinos with Disabilities. Chicago, IL.

Gibbons, H. M., & Gibbons, C. M. (2016). "Our siblinghood is like a mental health community in itself": A duoethnography by siblings with disabilities. Presented at the International Congress of Qualitative Inquiry. Champaign, IL.

Gibbons, H. M. (2016). Locked in, locked up: The influence of carceral logic on nursing homes in America's prison nation. Presented at the Engendering Change Graduate Student Conference. Chicago, IL.

Gibbons, H. M. (2016). The "failures" of "successful" aging: The impact of compulsory youthfulness on people with dementia. Presented at the Chicago Disability Studies Conference. Chicago, IL.

Gibbons, H. M. (2016). Dementia time: Extending crip time to engage with the politics of forgetting. Presented at Crip Futurities. Ann Arbor, MI.

Gibbons, H. M. (2015). Bringing a disability studies perspective to conversations on dementia and sex. Presented at Breaking Silences: Demanding Crip Justice: Sex, Sexuality, and Disability. Dayton, OH.

O'Leary, M. E., & **Gibbons, H. M.** (2015). Deviant sexuality: The hypersexualization of women with bipolar disorder. Presented at Breaking Silences: Demanding Crip Justice: Sex, Sexuality, and Disability. Dayton, OH.

Gibbons, H. M. (2015). The mad professor: Coming out as an instructor with a psychiatric disability. Panel presentation: Coming out/right: Navigating the complex territory of disability disclosure as women and emerging scholars. Presented at the Society for Disability Studies Annual Meeting, Atlanta, GA.

Gibbons, H. M. (2015). Conceptualizing dementia as a disability: Using a disability studies lens to explore the intersections of age and disability. Presented at the Annual Meeting of the North American Network in Aging Studies, Oxford, OH.

Heller, T., Owen, R., **Gibbons, H. M.**, & Schmidt, M. (2015). Perceptions of health and health care of people with IDD enrolled in Medicaid Managed Care. Presented at the

Annual Meeting of the American Association of Intellectual and Developmental Disabilities, Louisville, KY.

Heller, T., Owen, R., **Gibbons, H.M.**, Crabb, C., & Schmidt, M. (2015). Perceptions of adults with IDD and their families on health care of people with IDD and the transition to Medicaid Managed Care. Presented at the Annual NARRTC Conference, Alexandria, VA.

Gibbons, H. M. (2015). Caring for incarcerated people with dementia. Presented at the Chicago Disability Studies Conference, Chicago, IL.

Gibbons, H. M. (2014). Reinterpreting dementia stimulations through a disability studies lens. Presented at the Presented at the Annual Meeting of the Gerontological Society of America, Washington, D.C.

Heller, T., Owen, R., **Gibbons, H.M.**, & Mitchell, D. (2014). Aging with a physical disability in Medicaid Managed Care. Presented at the Presented at the Annual Meeting of the Gerontological Society of America, Washington, D.C.

Gibbons, H. M. (2014). Challenging the "never-ending funeral": Reinterpreting dementia through a disability studies lens. Presented at the Society for Disability Studies Annual Meeting, Minneapolis, MN.

Gibbons, H. M. (2013). "When people think of me, I want them to think of my personality– not my feet": Exploring the identities of college students with disabilities. Presented at the Society for Disability Studies Annual Meeting, Orlando, FL.

Andrews, G., **Gibbons, H. M.**, Ways, M. P., & McMahon-Klosterman, K. M. (2011). Refining frameworks for "Glocal" service-learning. Presented at International Partnership for Service-Learning Symposium, Siena, Italy.

Gibbons, H. M. & Ways, M. P. (2011). Service-learning: Putting theory to practice in the engaged university. Presented at the Engaged Teaching & Learning Expo, Oxford, OH.

Gibbons, H. M. & Manning, L. K. (2011). Successful service-learning syllabi. Presented at the Association for Gerontology in Higher Education Annual Meeting, Cincinnati, OH.

Manning, L. K. & **Gibbons, H. M.** (2011). The social networking effect: The presence of older adults in virtual networks. Presented at the Association for Gerontology in Higher Education Annual Meeting, Cincinnati, OH.

Manning, L. K. & **Gibbons, H. M.** (2009). Exposure to dementia through service-learning: Capturing students' attitudes about older adults with dementia. Presented at the Annual Meeting of the Gerontological Society of America, Atlanta, GA.

Gibbons, H. M. & Manning, L. K. (2009). Talkin' bout Myspace generation: The presence of the young-old in virtual networks. Presented at the Ohio Association for Gerontology in Education, Oxford, OH.

Gibbons, H. M. (2009). Linking lives: Improving intergenerational relations through service-learning. Presented at the Association for Gerontology in Higher Education Annual Meeting, San Antonio, TX.

INVITED LECTURES, KEYNOTES, & PANELS

Yoshizaki-Gibbons, H. M. (2019). Incorporating Disability Studies in the Study and Practice of Law. Invited Lecture for the Coelho Center for Disability Law, Policy, and Innovation. Loyola Law School. Los Angeles, CA.

Yoshizaki-Gibbons, H. M., Chung, S., Teh, K., Patrick, R., Pak, J. (2017). Challenging API Stereotypes: Storytelling within the Community. Invited Panelist. Coalition for API Disability Coalition and Asian Americans Advancing Justice. Chicago, IL.

Yoshizaki-Gibbons, H. M., Diaz, A., Gharib, A., Morgan, N., Murphy, S., & Rubin, B. (2018). Siblings with Disabilities Multicultural Roundtable. Invited Panelist. Sibling Leadership Network, Chicago, IL.

Gibbons, H. M. (November, 2015). Letting Go of "The Long Goodbye": Applying Disability Studies to Dementia. Invited Lecture for the Kate Welling Distinguished Scholars in Disability Studies Lecture Series. Miami University, Oxford, OH.

Gibbons, H. M. (April, 2013). Keynote Speaker at America Reads, America Counts, and Adopt A School Volunteer Reception. Miami University, Oxford, OH.

CONSULTATIONS & COURSE FACILITATIONS

Yoshizaki-Gibbons, H. M., Ohashi, N., Alcantar, J. (October 2019). Disabled People's Experiences in the American Medical System. Guest Lecture for HON 201: Cripping Medical Culture: What Disability Movements Can Teach Future Health Professionals. University of Illinois at Chicago. Chicago, IL.

Yoshizaki-Gibbons, H. M. (April 2019). Our Siblinghood is Like a Mental Health Community in Itself: The Relationship of Siblings with Disabilities. Guest Lecture for DHD 101: Disability in U.S. Society. University of Illinois at Chicago. Chicago, IL.

Yoshizaki-Gibbons, H. M. (April 2019). Disabled People's Experiences in Healthcare. Guest Lecture for HON 201: Cripping Medical Culture: What Disability Movements Can Teach Future Health Professionals. University of Illinois at Chicago. Chicago, IL

Yoshizaki-Gibbons, H. M. (November 2018). Disability Rights and Justice Movements. Guest Lecture for OCC 602: Introduction to Occupation, Health, and Wellness. Rush University. Chicago, IL.

Yoshizaki-Gibbons, H. M. (November 2018). Navigating Mental Health, Disability, Advocacy, and Self-Care. Guest Lecture for OT 494: Promoting Wellbeing. University of Illinois at Chicago. Chicago, IL.

Yoshizaki-Gibbons, H. M. (November 2017). Journeying into Dissertation Research: A Work in Progress. Guest Lecture for DHD 541: Advanced Concepts in Disability Research. University of Illinois at Chicago. Chicago, IL.

Yoshizaki-Gibbons, H. M. (April 2017). Guest on the "Disability Pride Podcast." Hosted and Edited by Winston Lindqwister.

Yoshizaki-Gibbons, H. M. (April 2017). Disability, Old Age, and Compulsory Youthfulness. Guest lecture for DHD 202: Disability, Health, and Society. University of Illinois at Chicago, Chicago, IL.

Yoshizaki-Gibbons, H. M. (April 2017). Feminist Disability Studies. Guest Lecture for WGSS 100: Introduction to Women's, Gender, and Sexuality Studies. Washington University, St. Louis,, MO.

Yoshizaki-Gibbons, H. M. (April 2017). Access and Inclusion in Disability Activism and Beyond. Guest Lecture for DST 375: (Dis)Ability Allies: To Be or Not to Be? Developing Identity and Pride from Practice. Miami University, Oxford, OH.

Yoshizaki-Gibbons, H. M. (February 2017). Ethnography in Disability Studies. Guest Lecture for DHD 546: Qualitative Methods in Disability Research. University of Illinois at Chicago. Chicago, IL.

Gibbons, H. M. (March 2016). My Experiences as a Mixed Race, White Passing Woman. Guest Lecture for SOC 316: Race and Ethnic Relations. Northeastern Illinois University. Chicago, IL.

Gibbons, H. M. (November 2015). What is Justice? Personal Reflections, Academic Connections, Intersectional Approaches. Guest Lecture for the Urban Teaching Cohort. Miami University, Oxford, OH.

Gibbons, H. M. (November 2015). Disability Studies as an Interdisciplinary Project: Intersections between Disability Studies, Gerontology, and Mad Studies. Guest Lecture for DST 272: Introduction to Disability Studies. Miami University, Oxford, OH.

Gibbons, H. M. (November 2015). Connections to K-12 Education: What Can We Learn from Applying Disability Studies to Dementia? Guest Lecture for the School of Education. Mount St. Joseph's University, Cincinnati, OH.

Gibbons, H. M. (October 2015). Navigating the Complexities of Being an Ally in the Disability Community. Guest Lecture for DST 375: (Dis)Ability Allies: To Be or Not to Be? Developing Identity and Pride from Practice. Miami University, Oxford, OH.

Gibbons, H. M., Patsavas, A., Owen, L., and Frank, K. (August 2015). Tips from a teaching assistant to a teaching assistant. Panel presentation for Disability and Human Development Teaching Assistant Orientation. University of Illinois at Chicago, Chicago, IL.

Gibbons, H. M. (July 2015). Cripping and Croning: Incorporating Disability and Old Age into Explorations of Intersectionality. Guest lecture for GWS 101: Gender in Everyday Life. University of Illinois at Chicago, Chicago, IL.

Gibbons, H. M. (May 2015). Infusing Disability Studies Perspectives into K-12 Education. Guest speaker for Professional Development Session. UIC College Preparatory High School, Chicago, IL.

Gibbons, H. M. (April 2015). Intersections of Aging and Disability. Guest lecture for DHD 202: Disability, Health, and Society. University of Illinois at Chicago, Chicago, IL.

Gibbons, H. M. (July 2014). Disability and Diverse Sexualities. Guest lecture for ED 640G: Diversity and Social Justice. Merrimack College, North Andover, MA.

Gibbons, H. M. (August 2013). Becoming an Ally to People with Disabilities. Invited presentation for Resident Assistant Training, DePaul University, Chicago, IL.

Gibbons, H. M. (July 2013). EMPOWER: Introduction to Social Justice Curriculum. Consultation for Urban Teaching Cohort and School of Education, Health, and Society. Miami University, Oxford, OH.

Gibbons, H. M. (January 2013). Becoming an Ally to People with Disabilities. Invited presentation for Professional Staff and Resident Assistants in Residence Life. Miami University, Oxford, OH.

ADMINISTRATIVE & PROFESSIONAL EXPERIENCE

ADMINISTRATIVE EXPERIENCE

Interim Assistant Director | Community Engagement & Service
Miami University | July 2010-June 2011

Service-Learning Coordinator | AmeriCorps*VISTA
Miami University | July 2009-June 2010

America Reads & Adopt A School Coordinator | AmeriCorps*VISTA
Miami University | July 2008-June 2009

GRADUATE EXPERIENCE

Research Intern | Bureau of Sages Project
Council for Jewish Elderly | January 2016-Present

Research Assistant | Know Your Rights, Illinois
University of Illinois at Chicago | August 2014-December 2014

Research Assistant | Disability & Human Development
UIC | January 2014-August 2015

Graduate Assistant | Urban Teaching Cohort
Miami University | August 2011-May 2013

AmeriCorps*VISTA | Hamilton Living Water Ministry
Ohio Association of Food Banks | Summer 2012

SERVICE TO THE CAMPUS & COMMUNITY

Member | Chancellor's Committee on the Status of Persons with Disabilities | UIC
September 2014-Present
- Appointed by the Chancellor to work towards empowerment and inclusion of students, faculty, and staff with disabilities at UIC.
- Serve as Chair of the Student Subcommittee, which involves representing the needs and concerns of undergraduate and graduate students with disabilities at UIC.
- Serve as Member of the Survey Subcommittee, which involves designing and implementing a campus climate survey for students, staff, and faculty with disabilities.

Volunteer | Memory Ensemble | Northwestern University & Lookingglass Theatre
January 2016-Present
- Assist in an improvisational theatre program for people with dementia.
- Engage in participant observation, take field notes, and assist with program evaluation and research.

Vice-President | Disability and Human Development Student Association | UIC
August 2016-May 2018
- Assist in planning and implementing academic support, professional development, and social events for graduate and undergraduate students in the Disability and Human Development department.
- Support the planning of the Chicagoland Disability Studies Conference

Steering Committee | Queer Caucus | Society for Disability Studies
June 2014-November 2016
- Assist in setting the vision, goals, and direction for the Queer Caucus.
- Provide support in planning for Queer Caucus panels, workshops, and business meetings at the Society for Disability Studies Conference.

Academic Committee Chair | Disability Studies Student Council | UIC
August 2015-August 2016
- Serve as a resource for students on issues related to courses or the curriculum for the PhD program.
- Assist in the planning of events such as CV Workshops, Reference Manager Workshops, and Preliminary Exam Workshops.

Departmental Representative | Graduate Student Council | UIC
August 2015-August 2016
- Serve as a liaison between the Graduate College and Department of Disability and Human Development.

Student Organization Advisor | Miami University
August 2008-May 2013
- Advised the Adopt A School, Clubhouse, Service-Learning Scholars, and Urban Leaders student organizations.

Faculty Learning Community on Professional Development | Miami University
August 2012-May 2013
- Worked to incorporate more career exploration and professional development into the College of Arts and Sciences and the School of Education, Health, and Society.

Urban Teaching Cohort Curriculum Committee | Miami University
August 2011-May 2013
- Provided guidance, standards, and oversight for the Urban Teaching Cohort curriculum.
- Assisted in the implementation of a Diversity Portfolio for the Urban Teaching Cohort students.

SL (Service-Learning) Course Designation Committee | Miami University
January 2009-May 2012
- Read course syllabi and approve courses that meet the requirements to become official SL (Service-Learning) Designated courses.

Faculty Learning Community on Global Learning | Miami University
August 2011-May 2012
- Participated in discussions on infusing global learning into the university's liberal arts curriculum.
- Shared suggestions for incorporating more "global" and "glocal" service-learning opportunities into the liberal arts curriculum.

GRANTS & SPECIAL PROGRAMS

Midwest Campus Compact Citizen-Scholars Program | $16,000
Fall 2009-Spring 2011
- Provided 8-16 first generation low-income students with $1,000 scholarships for completing 300 hours of service in one year.

Great Cities, Great Service Grant | $5,000
Fall 2009-Spring 2010
- Funded the Young Authors Program, a collaboration between Miami University and Hamilton Living Water Ministry, Inc. 2nd – 5th grade students wrote and illustrated their own books with the assistance of Service-Learning students from a Spanish education course.
- The Young Authors displayed their books during an end of year celebration open to the community.
- The Young Authors read their books to younger students on Global Youth Service Day.

Dollars for Change Grant | $2,000
Fall 2010
- Funded an intergenerational service-learning program that paired at-risk Talawanda High School Students with Miami University undergraduate students. Working together, the Talawanda and Miami students read books and facilitated literacy activities with elementary school students.

Youth Leaders for Literacy Grant | $500
Fall 2010
- Funded a literacy program about farming for inner city youth in Hamilton. Miami students read books about farming with K-12 students at Hamilton Living Water Ministry and they then visited a farm in Oxford, Ohio together. The books were gifted to the K-12 students to build their at-home library.

State Farm Good Neighbor Service-Learning Grant | $1,000
Spring 2009
- Provided startup funds for the Young Authors Program (see the Great Cities, Great Service Grant).

PROFESSIONAL MEMBERSHIPS

Society for Disability Studies
National Women's Studies Association
Canadian Disability Studies Association
American Studies Association
Gerontological Society for America

MEMBERSHIP ON UNDERGRADUATE THESIS COMMITTEES

- 2009-2010: James Ruoro Muruthi: Changes in Public and Cultural Policies and Older Women of Rural Kenya, Miami University, Oxford, OH.
- 2008-2009: Eva D'Intino: (Don't) Fall into the Gap: Using After School Programs and Culturally Relevant Curriculum Design to Close the Achievement Gap in Urban Schools, Miami University, Oxford, OH.

*Note: In 2017, I added my grandmother's maiden name, Yoshizaki, to my surname.