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Constellations of Complexity: Direct Care Workers' Lived Experiences of Marginalization and Blurring Boundaries

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Constellations of Complexity: Direct Care Workers' Lived Experiences of Marginalization and Blurring Boundaries

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CHAPTER 1: INTRODUCTION

I. Introduction

This dissertation is a study of the lived experience of direct care workers who provided essential care and services in individual homes for older adults in the United States during the COVID-19 pandemic. Direct care workers are an essential part of our care infrastructure, yet there is surprisingly little research centering their experiences whilst providing care and services in individuals' homes. Through this work, I argue that this workforce occupies a unique and vulnerable occupational position, often between family and non-family, and blurring traditional notions of personal and professional. I embarked on this journey to learn more about direct care workers' experiences providing care and services in individual homes, such as why they chose this type of work, especially as it is underpaid and undercompensated, what their day to day work looked like and meaning making attached to their work, and how they coped with losses inherent in this work. Namely, this dissertation aimed to address three primary research aims using qualitative interviews (n=43) and quantitative content analysis: 1.) To examine direct workers' experiences of work throughout the COVID-19 pandemic 2.) To understand how home care workers navigate and utilize resources and support mechanisms and 3.) To identify the processes in which home care workers practice self-care. As the data collection and analysis took place, this dissertation work broadened and evolved to focus primarily on the concept of blurring traditional conceptions of personal and professional boundaries, experiences during the COVID-19 pandemic, and what I call institutional disenfranchised grief.

My personal motivation for pursuing these topics stems from early life experiences in witnessing the care needs of aging family members. Growing up, my Grandmother was a spousal caregiver for my Grandfather for many years before he passed away. She was not paid for her work, which was physically and emotionally challenging for her and our family. Additionally, my paternal Grandfather suffered from Alzheimer's disease for many years before his death. In our low-socioeconomic status and rural community, it was difficult to find specialty memory care centers, travel to appointments, and afford necessary care. These experiences sparked questions about health equity and aging in U.S. society, as well as options for home and community-based care systems which started me on the path of exploring interdisciplinary approaches to aging, gerontology, and sociology and drew me to pursuing this work.

My grandparents' experience is like millions of others who experience increasing care needs as they age in place, needs which are often met by home care workers (or direct care workers providing care and services in individual homes). Literature suggests that 80% of older adults live in the community and not long-term care facilities (Hudson, 2014). Given that the majority of older adults live in the community and the demand for home and community-based services is steadily increasing in the U.S., experiences of direct care workers providing care and services in home care are important to explore. Authors argue that the long-term care system fails to meet the needs of older adults, their families, and direct care workers and has been focused on individual solutions to this structural issue partially because of a lack of acknowledgement that long-term care is a public need/issue (Levitsky, 2014).

Despite the increasing demand for home care as Americans age sicker, this workforce that is disproportionately comprised of women of color is underpaid and under-acknowledged in our society (Almeida et al 2021; Berry & Bell, 2012; Cranford, 2020; Loe, 2011; Laster Pirtle & Wright, 2021; PHI, 2018; Stacey, 2011). Direct care workers are a marginalized community that face physical and emotional labor inherent in this work and receive little institutional support even in their critical role in our long-term care system. In this dissertation, I sought to amplify the voices of direct care workers providing care and services to non-family older adults in their individual homes.

For this dissertation specifically, I conducted in-depth interviews with individuals who fit the Bureau of Labor Statistics definition of direct care workers: 1) nursing assistants (also known as CNAs) 2) personal care aides (PCAs) and 3) home health aides (HHAs) (U.S. Bureau of Labor Statistics, 2020). While direct care workers can provide care and services in many settings, such as nursing homes and community living facilities, I spoke with direct care workers who worked in individual homes. I also spoke to individuals whose jobs were described as home care aides or people who identified as home care workers broadly, and were paid for their labor in home care, meaning that they provided care and services in individual homes in the community. For recruitment purposes and my interest in exploring institutional support mechanisms, I focused on direct care workers employed at a home health or home care agency. The study population is the direct care workforce primarily providing care and services to non-family older adults in the U.S. that were paid for their labor and were employed at a home health or home care agency.

The timing of my research coincided with the shock of a global pandemic, which was a shock for everyone, but the nature of direct care work in individual homes put these workers in an especially vulnerable position. In March of 2020, the World Health Organization (WHO) declared that COVID-19 had become a pandemic. This tumultuous time brought attention to the fragmented healthcare system in the U.S. that was reaching capacity/stretching quite thin to a dangerous degree. Media was quick to spotlight and support hospitals, doctors, and nurses within those systems, and also spotlighted nursing homes and workers. However, there was little attention on direct care workers providing care and services in individuals' homes during this time, who faced challenges and difficult decisions in the midst of the pandemic. The COVID-19 pandemic disproportionately impacted older adults and care workers, as deaths in nursing homes (both residents and staff) range from 41% to 45% of all COVID-19 deaths in the U.S. yet can be as high as 80% depending on the state (Girvan & Roy, 2020; United Nations Policy Brief, 2020; Yourish, Lai, Ivory, & Smith, 2020). During the COVID-19 pandemic, direct care workers were considered frontline/essential workers with little support, and many agencies closed during the pandemic, switched to remote models, or continued sending workers into folks' individual homes. Amidst these circumstances, I aimed to amplify the voices of direct care workers to understand more about their nuanced experiences.

Literature often reflects opposing narratives around carework, typically discussing the challenging physical, emotional, and social work of direct care workers or discussing close, family-like relationships between direct care workers and clients. Spotlighting positive or negative experiences and consequences of care work does not capture a complete picture of nuance and complexity that direct care workers experience, and I argue that they occupy a more complex space, often experiencing blurring personal and professional boundaries - the work is simultaneously muddled and interconnected rather than just one of these at a time like the literature commonly reflects. I argue that direct care workers occupy a unique space betwixt/between family and caregiver, and they receive little social or institutional support around these fluid boundaries.

For the remainder of this introductory chapter, I first discuss more background information regarding the direct care workforce, such as demographic information for this workforce. Next, I discuss three major theoretical frameworks that align with analytical chapters, namely emotional labor, blurring boundaries/role conflict, and disenfranchised grief. Then, I provide a brief preview of the methods deployed in this dissertation. Lastly, I discuss a brief description of each chapter.

II. Background: The Significance and Attributes of the Direct Care Workforce

Direct care workers provide care and services to over 4.8 million older adults and people living with disabilities in the United States (PHI, 2023). The demand for home and community-based care continues to grow in the United States, especially as the population continues to live longer and age sicker. Home health care is a fast-growing occupation that is expected to grow by 34% from 2019-2029 (Bureau of Labor Statistics, 2019-2020). Because 80% of older adults live in the community and not in long-term care facilities, direct care workers' experiences are imperative to understand (Hudson, 2014; Loe, 2011). As the U.S. population ages and the demand for home care continues to rise, it is important to understand the experiences of the direct care workforce to bolster economic and social support at a systemic/institutional level for this critical workforce.

This workforce is disproportionately comprised of women of color whose labor is unrecognized currently and historically, and are poorly compensated for their work, receive few benefits in terms of vacation and sick leave, and whose labor is often invisible (Almeida, Cohen, Stone, & Weller, 2021; Berry & Bell, 2012; Institute on Aging, 2020; Loe, 2011; National Center on Caregiving, 2015; PHI, 2023; Pirtle & Wright, 2021; Stacey, 2011; Seavey, 2007). The median age for this group is 48 years old, meaning that they are a part of the 'sandwich generation' in which many adults care for both older parents and their own children that may add additional strain (PHI, 2023). Furthermore, recent research suggests that almost one half of the direct care workforce earns “less than a living wage” (Almeida, Cohen, Stone, and Weller, 2021: 122).

There are some similarities and differences regarding job scope for home health aides (HHAs), home care aides (HCAs), and nursing assistants (also called CNAs). This information largely comes from an issue brief by Hunt, Yeh, and Fix (2023). Home care aides, also known as personal care aides in some circumstances, largely provide custodial care and companionship services in individual homes, in the community, and in residential facilities. Home health aides provide custodial care, companionship services, and skilled medical care and can work in the same settings as home care aides. Nursing assistants (or certified nursing assistants) or CNAs provide the same types of care as home health aides, and can provide care in different settings such as skilled nursing facilities and hospitals as well as community and residential care facilities. For the purposes of this dissertation, it is important to note that I spoke with people working in all three of these occupational categories who may differ in types of care given but all participants worked in individual homes at the time of their interview.

III. Theoretical Frameworks

Three theoretical frameworks inform and structure the analysis at the heart of this dissertation and are woven into the subsequent chapters of this dissertation: 1) intersectionality and structural oppression 2) emotional labor 3) blurring boundaries and role conflict and 4) disenfranchised grief.

Intersectionality and Structural Oppression

Intersectionality and oppression, such as structural oppression and structural gendered racism, are imperative to discuss as part of this dissertation. As the majority of direct care workers identify as women of color, which is reflected in the analytic sample of this dissertation, I felt that it was important to explore and discuss intersectionality and the rampant racism in the United States and the ways this can shape work, mental health, and life in general.

Based on the body of literature regarding direct care work in individual homes, I expected participants to discuss various facets of discrimination and systemic oppression, such as microaggressions, and the ways in which these interactions shaped work and life for these workers. However, I found that participants rarely discussed racism, discrimination, and related topics in the interviews. There are several potential reasons why these topics did not often arise in the interviews. One potential reason why discrimination and racism did not typically arise in interviews is my own positionality as a white woman. Additionally, all interviews were conducted over the phone and not face-to-face, which may have impacted participants' comfortability discussing how intersecting oppression shaped their work and/or lives. Participants may have been focused on other salient experiences, in particular, discussions about their experiences related to the COVID-19 pandemic.

In this section, I discuss the ways in which my research has implications regarding inequity and how intersectionality (specifically race, gender, and age) shapes experiences for direct care workers. These theories provide an overarching lens describing the sociocultural milieu in which direct care workers live and work. However, these theories are not as applicable to the analytic chapters specifically and therefore I will not be engaging with this framework in the same depth as the other theoretical frameworks throughout the analytic chapters.

The theoretical framework of intersectionality as well as the concepts of structural oppression and structural gendered racism are important to understand the experiences of direct care workers, as people are always already existing in various racial, gender, age, and class locations which intersect and interact to shape experiences (Brown & Homan, 2023; Cho, Crenshaw, McCall, 2013; Collins, 1998; Crenshaw, 2019; Homan, Brown, & King, 2021; Pirtle & Wright, 2021). Throughout my dissertation I planned to use an intersectional approach to analyze data and acknowledge the intersection of various identities and the ways in which these impact experiences, mental health, relationships, and emotional labor. Additionally, I discuss the notion of structural gendered racism, which aims to demonstrate "the totality of interconnectedness between structural racism and structural sexism in shaping race and gender inequities," to highlight the invisible labor by women of color working as direct care workers (Pirtle & Wright, 2021:1). Further, structural oppression permeates the social milieu in which we live, particularly in the United States context. New concepts about structural intersectional oppression highlight that "overlapping systems of oppression intersect with race and gender statuses to shape health…intersecting structural inequalities are most consistently associated with poorer health for black women" (Homan, Brown, & King, 2023: 13).

Furthermore, the theories of structural racism and discrimination can better illustrate the dynamic experiences of direct care workers that complicate binary studies typical of this research topic focusing only on gendered or classed experiences. Between one half and two thirds of direct care workers are women of color who often face racism, discriminatory policies, and exploitation while at work (Boris & Klein, 2012; Cranford, 2020; National Alliance for Caregiving, 2020; PHI, 2018; Parks, 2003; Stacey, 2011). As the majority of direct care workers are women of color in the U.S., it is imperative to discuss the ways in which systems of oppression shape work, health, and the experiences of this critical workforce.

Gendered Inequities and the Direct Care Workforce

This dissertation work has implications for gendered inequities associated with this workforce, as the majority of caregivers are women whose labor is deeply undervalued in the U.S., demonstrated by low wages, minimal benefits such as health insurance or vacation time, and the invisibility of emotional and social labor in such work. Feminist scholars Fisher and Tronto, as well as Mignon Duffy argue for complex understandings, theories, and analyses of women's experiences of caregiving which, they argue, is a social process shaped by context that includes historical context, inequalities, and identities such as race, class, and gender (Fisher and Tronto, 1990). Direct care workers' labor is indeed exploited by the capitalist system in the United States, and women have different and changing experiences of caregiving within this system which is shaped by social processes and identities (Abel & Nelson, 1990; Boris & Klein, 2012; Cox, 2015; Fisher & Tronto, 1990).

Hochschild described that women are more likely to be employed in jobs which require emotional labor, and it is evident that more than half of caregivers are women currently and historically (Boris & Klein, 2012; Cox, 2015; Hochschild, 1983; Hudson, 2014; O'Rand & Henretta, 1999; Rowles & Teaster, 2016). This illuminates a gendered and racial divide in occupational status, and feminist ethicists argue that the capitalist system in the United States exploits women as caregivers, driving medical costs down by underpaying, undervaluing, and deskilling this work (Armstrong, 2013; Berry & Bell, 2012; Cranford, 2020; Dodson & Zincavage, 2007; Parks, 2003). The social and emotional labor inherent in caregiving by women is undervalued and often invisible because it is seen as "just an extension of domestic labor" and therefore perceived as unskilled (Aronson & Neysmith, 1996: 3; Diamond, 1992; Foner, 1994; Guy, Newman, & Mastracci, 2015; Rodriquez, 2014; Vora, 2017). This is important because it highlights “that women have [historically] done, and still do, most of the caregiving in our society” and is directly applicable to the direct care workforce (Gordon, Benner, & Noddings, 1996: 274).

Women often face more labor at home after work in comparison to men, called the “second shift,” which may impact direct care workers (Hochschild & Machung, 1989/2012). According to Hochschild and Machung, the second shift occurs when returning home from working the ‘first’ shift at work. A participant from their work described this as being constantly on duty both at work and at home: “you’re on duty at work. You come home, and you’re on duty. Then you go back to work and you’re on duty” (Hochschild & Machung, 1989/2021: 7). Hochschild and Machung studied “two-job” married couples to understand their experiences of work, child-rearing, and tending to the house. Although experiences of the second shift differed per couple, their research suggested that women do 2 weeks of 24 hour days more work than men caring for children and the household. This indicates that women are more responsible for the second shift. Overall, this work suggests that the gendered division of labor even among 2-job couples still places burden and responsibilities disproportionately on women. As the direct care workforce is mostly comprised of people who identify as women, research suggests that they may face additional labor by doing the second shift.

The median age of home care workers is 48 years old, falling within the parameters classified as part of the ‘sandwich generation’ (PHI, 2023). The sandwich generation is a term which describes adults caring for their older parents as well as their own children. Regarding this matter, one study stated that “…an increasing proportion of women will be in the position of providing care to both children and elderly parents…” (O’Rand & Henretta, 1999: 94). There is an increasing prevalence of women caring for both their parents and children especially among direct care workers. Furthermore, research suggests that caregivers in this situation are more vulnerable to COVID-19 given their work and close contact with both older adults and younger children (Stokes & Patterson, 2021). Direct care workers may experience additional labor as part of the ‘sandwich generation’ that provides care to their young children, parents, and older adults at work.

Racial Inequities and the Direct Care Workforce

Given that the majority of caregiving work is disproportionately done by women of color, findings have implications for racial inequality (Berry & Bell, 2012). As the U.S. population continues to grow older and sicker, the proportion of caregivers identifying as women of color is increasing as well. Women of color make up over 66% of all direct care workers (Almeida, Cohen, Stone, & Weller, 2021; Berry & Bell, 2012; Loe, 2011; Pirtle & Wright, 2021; PHI, 2023; Seavey, 2007). As direct care workers, many women of color face discrimination at work, which may worsen physical and mental health outcomes (Blue Cross Blue Shield, 2020; Cranford, 2020; Paradies et al., 2015; Stacey, 2011). Some anti-racist feminist scholars argue the field of emotion work can be white-centric, so it is imperative to discuss intersectionality to better understand emotional labor for direct care workers who are disproportionately women of color.

Women of color working as direct care workers often face racial discrimination at work at institutional and individual/interpersonal levels, which demonstrates how systems of oppression shape this work. Using the nationally representative National Home Health Aide Survey (NHHAS), one study found that 23% of Black home health aides reported experiencing racial discrimination at work (Lee, Muslin, & Mcinerney, 2016). Using the NHHAS, another study found that 24% of people of color reported discrimination at work, noting that the NHHAS was only offered in English and therefore this number may be an underestimate of home health aides' experiences of racial discrimination (Jang et al., 2017). Another study found that among low-income union workers in the Boston (U.S.) area, 44% of Black workers reported experiencing racial discrimination at work (Krieger et al., 2006). Qualitative works contextualize and explain examples of these experiences, including home care workers who were regularly accused of stealing from clients, were told to do housework and not touch clients, and faced clients that yelled harmful racial slurs (Cranford, 2020; Stacey, 2011). In their study of home health aides, Cranford stated that "not all workers of color recounted explicit racial slurs, fears of violence, or overt rejection, but most discussed being treated like a servant" (Cranford, 2020: 125). The majority of the participants in this dissertation identified as women of color who may face discrimination at work.

Literature details the ways in which institutional racism contributes to disparities in health outcomes which could make nearly two thirds of direct care workers more vulnerable to emotional labor (via stress and burnout) as well as to COVID-19 (Yearby, 2020). A meta-analysis of 293 studies found that "racism was associated with poorer mental health…physical health…[and] poorer overall health" (Paradies et al., 2015). Other studies demonstrate health disparities for caregivers specifically. For example, Black direct care staff are more likely to experience strain and burnout (Shippee et al., 2021). According to another study, caregivers that identified as Black or Hispanic reported worse health outcomes than white caregivers (Blue Cross Blue Shield, 2020). Another study found that Black and Hispanic or Latino respondents had higher rates of anxiety and/or depression than white respondents (Panchal, Kamal, Cox, & Garfield, 2021). An American Psychological Association report found that "people of color are more likely than white adults to report significant stressors in their life as a result of the coronavirus pandemic" (American Psychological Association Report, 2020). It is evident that racism contributes to racial disparities in health overall and for caregivers more specifically. Structural racism impacts institutions, client-staff relationships, and shapes experiences of direct care workers.

Emotional Labor as a Framework for Exploring Direct Care Workers' Experiences

Direct care workers perform emotional labor in the workplace by caring for both the physical and mental health of older adults, and I utilize the theoretical approach of emotion work to examine their experiences throughout this dissertation. Arlie Hochschild, the scholar who first founded the term emotional labor, estimated that "roughly one third of American workers today have jobs that subject them to substantial demands for emotional labor" (Hochschild, 1983: 11). In her work, Hochschild explained that "emotional labor mean[s] the management of feeling to create a publicly observable facial and bodily display" (Hochschild, 1983: 7). By providing care and services for clients' physical, mental, and emotional well-being, direct care workers perform emotional labor at work.

Emotional labor may have significant negative consequences, putting caregivers at higher risk for stress, burnout, anxiety, depression, psychological distress, and earlier death (Brackey, 2017; Dodson & Zincavage, 2007; Hochschild, 1983; Jeung, Kim, and Chang, 2018; Lopez, 2006; National Center on Caregiving, 2015; Rowles and Teaster, 2016; Stacey, 2011). The COVID-19 pandemic may further exacerbate the negative consequences of emotional labor for direct care workers, as it has heightened job insecurity, job risk, and strained care workers' mental and physical health (United Nations, 2020). This has important implications for direct care workers' mental health and support mechanisms throughout this unprecedented time.

The emotional labor of direct care work may also have some positive aspects, but these positive aspects and results of providing care are often missing from accounts of caregiving and is significantly less explored in the literature. Though the majority of the literature is focused on negative consequences of caregiving, some works highlight that there may be positive aspects of caregiving as well. These aspects may include reciprocity and conceptions of selfhood around caring for others. Furthermore, providing care and services may forge deep friendships and relationships, such as fictive kin relationships. Fictive kin relationships are close bonds between a caregiver and client that are mutually beneficial, valued by both caregiver and client, and are rewarding (Dodson and Zincavage, 2007; Karner, 1998; Stacey, 2011). In these relationships, the caregiver becomes like family through the bond of providing care (Dodson and Zincavage, 2007; Karner, 1998; Stacey, 2011). Karner (1998) described fictive kin relationships, such that "those who *provide care like family* and *do what family does are* given the label of kin with its attendant affection, rights, and obligations" (Karner, 1998: 70). Some works specifically discuss the ways in which direct care workers are treated like family by clients and value their relationship and the social support resulting from it (Almeida, Cohen, Stone, & Weller, 2021; Aronson & Neysmith, 1996).

Literature suggests that there are both positive and negative experiences that arise from the emotional labor in care work, though more frequently feature negative aspects of this work, and commonly only highlight one or the other. Throughout this dissertation, I sought to incorporate positive and negative experiences as well as an exploration of the nuance of direct care workers' experiences.

The Invisibility of Emotional Labor for Direct Care Workers

The framework of emotional labor is a useful lens for this dissertation as a way to understand more of the invisible labor for the direct care workforce, as they are often required to do emotional labor at work, which occurs when they actively work to cultivate or reduce certain emotions in compliance with feeling rules imposed by job restrictions via employers (i.e. institutions such as home health agencies or private clients/employers). For example, direct care workers often must comply with certain requirements like maintaining "professionality" that is reflected in detachment or are expected to be warm and cordial at all times, or sometimes held to both of these standards. Emotional labor is closely tied to Goffman's notions of impression management. Hochschild further elaborates, stating that "the individual often works on inducing or inhibiting feelings so as to render them 'appropriate' to a situation" in accordance with feeling rules in the given situation (Hochschild, 1979:551). Part of emotional labor occurs when feeling rules dictate what emotions are acceptable and when, as well as requiring, restricting, or shaping behaviors and actions based on those feelings that are implemented and enforced by larger institutions (Hochschild, 1983). Hochschild further discusses responses to feeling rules, describing "emotion sanctions" which refers to the internal or external policing of emotions, enforcing what one should feel in certain situations (Hochschild, 1979:567). Direct care workers perform emotional labor at work when they control their emotions according to the designated feeling rules.

Emotional labor can provide a lens for understanding the challenges that direct care workers face throughout their work. In general, occupations that are demanding in terms of emotional labor have negative implications for mental and physical health for caregivers, as well as the self, due to depersonalization and alienation in response to emotional labor (Hochschild, 1983; Wolkomir & Powers, 2007). Specifically, emotional labor and mental health outcomes have been more recently researched in family caregivers and caregivers working in nursing homes. In these studies, researchers found that emotional labor often contributes to and heightens the risk for stress, burnout, anxiety, depression, psychological distress, illness, and earlier death for caregivers (Brackey, 2017; Dodson & Zincavage, 2007; Hochschild, 1983; Hudson, 2014; Jeung, Kim, and Chang, 2018; Lopez, 2006; National Center on Caregiving, 2015; Rowles and Teaster, 2016). More recently, studies about direct care workers detail emotional labor and stress (Cranford, 2020; Stacey, 2011). This becomes apparent with high turnover rates and burnout, which was recently included in the International Classification of Diseases as an occupational phenomenon by the World Health Organization (WHO, 2019). Emotional labor for direct care workers can contribute to worse health outcomes and may negatively impact the self in some cases (Hochschild, 1983).

The dominant neoliberal ideologies in the medical system including cost-cutting and economic efficiency extend to the work of direct care workers which can exacerbate the negative consequences of emotional labor. Neoliberal ideologies inherent in the business and medical model of care common in the U.S. healthcare system emphasize feeling rules related to detachment and depersonalization as facets of "professionality" as well as interacting with older adults in a "pleasant manner". Institutions, namely home health agencies and home care agencies that employ many direct care workers, often align with harmful neoliberal ideologies including the business model of care that requires depersonalization and restriction of emotion in favor of economic efficiency. Emotional labor and feeling rules for detachment and 'maintaining professionality' by portraying "emotions minimally" may significantly impact caregivers' abilities to care for themselves and others. This may be harmful to whole person care or person-centered care, as well as to direct care workers' well-being.

Often missing from traditional accounts of emotional labor is the potential positive outcomes from emotional or relational labor for direct care workers. Some positive aspects regarding caregiving are fictive kin relationships, conception of selfhood around helping others, and healing and gratification that can result from caregiving. Some works note that direct care workers are treated like family by clients and value their relationship especially in terms of social support (Almeida, Cohen, Stone, & Weller, 2021; Aronson & Neysmith, 1996). As direct care workers work with a small number of clients frequently and for many hours at a time, they often form a family like bond, blurring the boundary between the role of worker versus fictive kin as they struggle to separate the professional and personal. Forming close bonds are seen as integral to providing good person-centered care yet can also heighten risks for exploitation and abuse for direct care workers (Karlsson et al., 2019). Throughout this dissertation, I aimed to highlight the complexities and nuances of direct care workers' experiences, leaving room for direct care workers' positive experiences and meanings while also exploring the challenges they face and more complicated experiences that do not fall into either a positive or negative category.

Emotional Labor: Heightened Risk for Women of Color

Although the subsequent analytic chapters do not explicitly discuss racial disparities for this workforce, I would be remiss if I did not mention it here. This is more thoroughly discussed in the conclusion chapter but is necessary because identity and positionality are important to consider, especially for this workforce that is comprised disproportionately of women of color who face challenges in this occupation and U.S. society in general as they are entrenched in systems of intersecting oppressions. Literature highlights that people of color experience additional emotional labor at work in white-centric institutions in the U.S. In one study, authors examined how race and discrimination shaped experiences of emotional labor for students in law schools as well as those in aviation such as pilots and flight attendants in the United States (Evans and Moore, 2015). Evans and Moore (2015) explore the ways in which people of color experience "an unequal distribution of emotional labor as a result of negotiating both everyday racial micro-aggressions and dismissive dominant ideologies that deny the relevance of race and racism" (Evans and Moore, 2015: 439). These authors highlight how people of color face additional emotional labor in white-centric spaces which claim to be "racially neutral (or equal)" (Evans and Moore, 2015: 441). The study noted various coping mechanisms and forms of resistance, including distancing themselves (a theme already seen in the emotional labor section of this dissertation) and complex decisions regarding if, when, and how to respond to racist remarks, assumptions, and microaggressions (Evans and Moore, 2015). Here, it is evident that people of color experience more emotional labor in various white-centric institutions in the United States through systemic and personal racism.

Women of color may face additional emotional labor at work. The U.S. healthcare system as an institution systematically mistreated and excluded people of color and women in particular. The majority of direct care workers are women of color entrenched in this system and therefore experience more emotional labor due to racism and discrimination, much like the adjacent case of nurses. One study examined experiences of nurses within the U.S. healthcare system through analyses of audio diaries which found that nurses experienced additional stress due to racism and discrimination at work especially via overt statements such as name-calling and microaggressions often featuring a questioning of their occupational competency/status (Cottingham, Johnson, & Erickson, 2018). The authors explained that "women of color experience an emotional double shift as a result of negotiating patient, coworker, and supervisor interactions" (Cottingham, Johnson, & Erickson, 2018: 145). This is consistent with the findings from Evans and Moore (2015) which also highlight that women of color in white-centric institutions (elite law schools and the aviation industry) face additional emotional labor especially stemming from discrimination and microaggressions from co-workers, supervisors, and passengers (aboard planes). Overall, these studies highlight that women of color encounter greater burdens of emotional labor especially in white-centric institutional spaces such as the U.S. healthcare system. Women of color comprise the majority of the direct care workforce, who face challenges within intersecting systems of oppression at work.

Blurring Boundaries and Role Conflict

In this section, I detail how direct care workers providing care and services in individual homes often experience blurring boundaries, otherwise known as role conflict or role ambiguity, in which professional and personal spheres blur and what constitutes professional and/or personal become unclear. I argue that these blurring boundaries can exacerbate emotion work for the direct care workforce because feeling rules, expectations around place and space (working in individual client's homes), and perceptions of family-like and non-family relationships are vague and fluctuate over time. It is unclear whether direct care workers should be warm and loving or detached and professional, or how these concepts change, shift, and blur.

There are many competing tensions in direct care work in individual homes, such as navigating boundaries when providing professional care and services while also in someone's home setting, forming a relationship that is seen as integral to good person-centered care, and yet receiving societal and institutional messages and expectations about professionality such as not getting "too close" to clients (Mears, 2009). Navigating these boundaries and expectations can be difficult, often resulting in blurring professional and personal boundaries. Researchers often describe this phenomenon as role conflict or role ambiguity, and often focus on tension around personal and professional boundaries. For example, researchers describe that paid care workers in the home occupy an "ambiguous position described by informants as a liminal status, which is characterized by the ambiguity of being 'betwixt and between' two culturally defined social positions," of family and professionals, meaning that they are sometimes perceived and constructed as family members and at times are not perceived or constructed as family (Barnhart, Huff, and Cotte, 2014:1686). This is often described as role conflict, which "may occur because home care work takes place in an environment which assumes a dual function: it is a person's home and a place of work" (Denton, Zeytinoğlu, & Davies, 2002:5).

This blurring of the personal and professional boundaries often resulted in a variety of consequences for participants throughout this dissertation, such as performing additional labor outside of requirements by the agency. Other research, though very limited, documents how blurring boundaries can result in additional unpaid labor beyond the expectations/requirements of the home care/home health agency (Mears & Watson, 2008). Further, researchers argue for notions of more fluid and flexible boundaries in home care settings guided by support from peers, supervisors, and their organization/agency which may positively impact quality of care and health outcomes for this workforce. I argue that intrinsic motivations for joining the direct care workforce, unclear feeling rules and expectations, and the care setting of individual homes contributes to these blurring boundaries. Through this dissertation, I explore these tensions and blurring boundaries and contribute to the limited literature on this topic.

I have described how direct care workers providing care and services in individual homes often form close bonds with clients, which can stem from their personal motivations for joining this workforce, the nature of this work, and the frequency and amount of time spent with clients. These reciprocal relationships are often described as "family-like" which highlights the blurring boundaries of traditional personal and professional spheres. Despite their family-like relationships with clients, direct care workers often did not receive family-like support socially or via institutions (home health/home care agency) especially when experiencing the death(s) of their client(s).

Disenfranchised Grief

Direct care workers have been shown to experience disenfranchised grief wherein their grief over the loss of their clients is not often acknowledged or supported in society or in their agencies/places of employment. Disenfranchised grief “refers to a loss that cannot be openly acknowledged, socially sanctioned or publicly mourned” (Doka, 2005:87). Some common examples of disenfranchised grief include grief regarding an ex-spouse, the loss of a loved one due to “stigmatized death” such as suicide, or the loss of a pet (PsychCentral, 2021). Other definitions of disenfranchised grief in the field of nursing, for example, state that “disenfranchised grief is experienced during bereavement loss and after the loss of something personal, physical, or psychological in which a person lacks societal witnessing, empathy, or validation of their loss” (Weiss, Florell, Oman, & Sousa, 2023:92).

Additionally, research notes a layering of loss for direct care workers which speaks to the cumulative nature of these losses over time (Marcella and Kelley, 2015). Other research suggests that direct care workers in home care experience not only the loss of a close person and but also a loss of finances when clients pass away (Riesenbeck, Boerner, Barooah & Burack, 2015; Wladkowski, Kusmaul, & Latimer, 2021). Lastly, literature notes how administrative systems lack ‘formal’ processes and opportunities for care workers to navigate grief and death of their clients. Despite the known consequences of grief and lack of administrative support, little qualitative research with direct care workers specifically details processes of grief and loss.

Research demonstrates that direct care workers may face consequences of grief similar to family caregivers and that closeness of client relationships may deepen grief processes as they often develop “family like” ties (Boerner et al., 2015:215). This grief can also contribute to burnout and mental health issues, which are often overlooked (Boerner, Gleason, & Jopp, 2017:317). Other literature points to the cumulative nature of grief, such that experiences of death add up over time (Marcella and Kelley, 2015). Additionally, research notes that preparedness for client death and closeness of client/caregiver impacted the grieving process, such that grief intensified the closer the relationship (Boerner, Burack, Jopp, & Mock, 2015; Anderson & Gaugler, 2007).

Literature notes how administrative systems lack ‘formal’ processes and opportunities for care workers to navigate grief and death of their clients. For example, one qualitative study with administrators and supervisors from continuing care retirement community (CCRC) facilities found that “only 3 of the 10 administrators discussed the importance of extending [bereavement] services to the staff” and noted a lack of “formal” support systems offered through employers (Chahal, Ewen, Anderson, & Miles, 2015).

In the COVID-19 pandemic and before/beyond, direct care workers experienced the deaths of their clients. In this dissertation, I explore direct care workers’ experiences with grief and loss. As they are providing care and services to older adults, clients often transition to hospice or palliative care before passing away. Direct care workers were perceived to be family and yet not family, and not given family like support and resources especially as their clients died. Despite regularly encountering the deaths and losses of their clients, direct care workers in home care receive little institutional support from home care or home health agencies.

These theoretical frameworks and lenses provide some background for what I explore throughout the analytic chapters of this dissertation. The methods for investigating the working conditions, requirements for joining this workforce, and pay rates begin with a quantitative analysis of job advertisements online for home health aides specifically. The bulk of the dissertation, however, centers direct care workers' lived experiences via qualitative semi-structured interviews. These in-depth interviews are the best way to explore these complex processes and relationships especially regarding emotional labor, role conflict, and disenfranchised grief for this critical workforce. Now, I turn to a discussion and overview of these methods.

IV. Methods

This dissertation features both a quantitative and qualitative analysis. For the quantitative portion of the dissertation, I performed a quantitative content analysis using (n=312) job advertisements for home health aides to understand the relationship between emotional labor and pay rates. For more specific information about the quantitative analysis portion of this dissertation, please see chapter two (methods chapter) and chapter three (the full quantitative content analysis chapter).

Definitions of this study population, namely direct care workers and home care workers, are complicated because many are family members, friends, and spouses for those they care for, which overlaps with the category of family caregivers. This work focuses on paid direct care workers providing care and services primarily to older adult non-family members and were employed at a home health or home care agency. There are over 11,400 home health agencies in the U.S., and there are 1 million home care workers who are independent workers that are not part of a home health agency (CDC, 2023; PHI, 2023). Constellations of employment in care work are complex and often overlapping, which include the 'grey' market wherein individuals hire direct care workers (Shih et al., 2022; Batalova, 2023).

For the qualitative analysis of this dissertation, I used semi-structured interviews with (n=43) direct care workers to understand their experiences of work throughout the COVID-19 pandemic. Charmaz's (2014) constructivist grounded theory (CGT) guided data collection and analysis for this portion of the dissertation. For more information about methods for the qualitative sections of the dissertation, please see a detailed description in chapter two (methods chapter) and chapter five (experiences of COVID-19 chapter). Each chapter based on qualitative interview data will contain a small methods section primarily discussing chapter specific methodological considerations such as codes, demographic information for participants, etc.

V. Dissertation Overview

The following section includes a summary of each chapter of this dissertation.

Chapter two describes methods in more detail, such as descriptions of the study population, recruitment processes, data collection, and data analysis for both the quantitative and qualitative portions of this dissertation.

In chapter three, I use content analysis and quantitative methods to address three primary research questions: 1) what are the prevailing pay rates for home care workers and how do they compare to living wages? 2) what is the relationship between emotion work requirements and pay rates in home care job advertisements? and 3) What happens to that relationship when stratified by home health agency size? Using online job advertisements for home care workers (n=312) across 10 large cities in the U.S., I found that in about 57% of the job advertisements hourly wages were not sufficient to meet the living wage level according to the MIT Living Wage Calculator which contextualizes the living wage level geographically. Using linear probability models, I found that there is no statistically significant difference between pay rates listed by home health agencies requiring emotional labor and home health agencies not requiring emotional labor while holding education, experience, and licensure requirements constant. This chapter demonstrates that home health aides are undercompensated for their labor and especially for emotional labor, even when stratifying the data by agency size.

In chapter four, I discuss how direct care workers experienced blurring personal and professional boundaries. In the (n=43) in-depth interviews, nearly all the direct care workers I spoke with had intrinsic motivations for joining the direct care workforce, such as family ties to caregiving, witnessing the death or care work of a family member, giving back to the community, or feeling like this work was a calling. Given the often deeply personal and experiential ties to this work, the close relationships with clients, and the setting of this work in individual homes, direct care workers often experienced blurring boundaries between the traditional conceptions professional and personal arenas, which created unique challenges such as additional labor, hesitancy to be away from clients, and challenges creating or upholding these boundaries. Chapter four features three main sections: 1) motivations for caregiving 2) doing additional labor 3) hesitancy being away from their clients.

Drawing on (n=43) in-depth interviews with direct care workers, findings from chapter five suggest that they experienced challenges both personally and professionally working within home care/home health agencies during the COVID-19 pandemic. As direct care workers shifted between interactions with their clients, whom they often formed close relationships with, and their spouses, children, and other family members at home, they experienced fear regarding the spread of the virus. Furthermore, some participants discussed their frustration at their state or home care/health agency during this time in the pandemic. Lastly, many of the direct care workers I spoke with noted how they should be perceived as an integral part of the health care team especially as frontline workers throughout the COVID-19 pandemic. In chapter five, I demonstrate that direct care workers experienced heightened fear, stress, and frustration during the COVID-19 pandemic and explore 5 main facets: 1) fear and panic during the onset of the pandemic 2) caught in between, caregivers worried for their families and their clients 3) using multiple “layers of precaution” such as masking, vaccinations, etc. to cope with stress and worry 4) frustration at the state and agencies and 5) recognition and acknowledgement that home care workers are integral to the health care team.

In chapter six, I argue that direct care workers providing care and services for non-family older adults in the U.S. experience disenfranchised grief. Direct care workers are critical in our long-term care system, especially in the home and community-based care system in the United States. Despite the known consequences of grief and lack of administrative support, little qualitative research with direct care workers specifically details processes of grief and loss. Drawing from (n=43) in-depth interviews, this work highlights that direct care workers and clients form close, family-like relationships and yet do not receive or have access to family-like support systems when their clients die (both personally and at an institutional level). I argue that direct care workers are vulnerable to and experience disenfranchised grief due to 1) the social construction of their relationship with clients that does not see the grief as legitimate, that they are not close enough, etc. and 2) further erasure and/or delegitimization of their experiences by a lack of agency/institutional support. This work has important implications for policy implementation and practices to better support direct care workers navigating grief when their clients die. Some examples for financial and social support include paid bereavement leave, mental health coverage under insurance, and peer-support groups.

Chapter seven concludes the dissertation first with a synthesis of findings. Next, I situate larger societal structures, such as intersecting systems of oppression, that impact and shape experiences of work for direct care workers. Then, I discuss implications for policy and practice which could provide improved support for this critical workforce. Lastly, I discuss future directions for research.

CHAPTER 2: METHODS

I. Introduction

In this chapter, I discuss the qualitative and quantitative methods deployed throughout this dissertation. I used quantitative methods to understand common job requirements for home health aides and to examine the relationship between pay rates and emotional labor for this critical workforce via a content analysis at a national level. For the quantitative component, I looked at job advertisements through Indeed.com which illuminated how home health aides are undercompensated for their work and especially for emotional labor. Through this dissertation, I also used qualitative in-depth interviews because I wanted to understand direct care workers' lived experiences. I used constructivist grounded theory (CGT) to focus on understanding complex and nuanced processes and experiences of work for direct care workers providing care and services for non-family older adults throughout the COVID-19 pandemic. I used constructivist grounded theory to guide data collection and analysis for this work.

The following sections provide more detail about the methods used throughout this dissertation. First, I detail how I used constructivist grounded theory to guide this dissertation work, how GCT principles aligned with the aims of this work, and the role of memos throughout this process. Next, I discuss researcher reflexivity and positionality that shaped this work. Then I highlight recruitment, study population, and sampling for the qualitative portion of the dissertation. Next, I discuss data collection for both the semi-structured interviews and the quantitative portion of the dissertation. Lastly, this chapter concludes with a discussion of data analysis for both the qualitative and quantitative methods deployed in this work.

II. Constructivist Grounded Theory Approach

I deploy constructivist grounded theory as the methodological approach for this dissertation (Charmaz, 2014). I applied constructivist grounded theory principles throughout this dissertation, which included researcher reflexivity, a focus on processes rather than themes, reaching data saturation, and concurrent data collection and analysis. I engaged in concurrent data collection and analysis and continued to conduct qualitative interviews until I reached theoretical saturation (n=43). For my dissertation, the concurrent data collection and analysis is beneficial because it allows the data to further inform the interview guide and to make changes where necessary.

For this dissertation in particular, it was important to more deeply understand the nuances of direct care workers' experiences with work, navigating support mechanisms, and processes of self-care which were achieved using CGT. Overall, this focus on understanding processes creates a different, more nuanced, and narrative story about the processes involved in work for direct care workers. Furthermore, it is important to acknowledge that both researchers and participants are engaged in constructing reality through research (Charmaz, 2014).

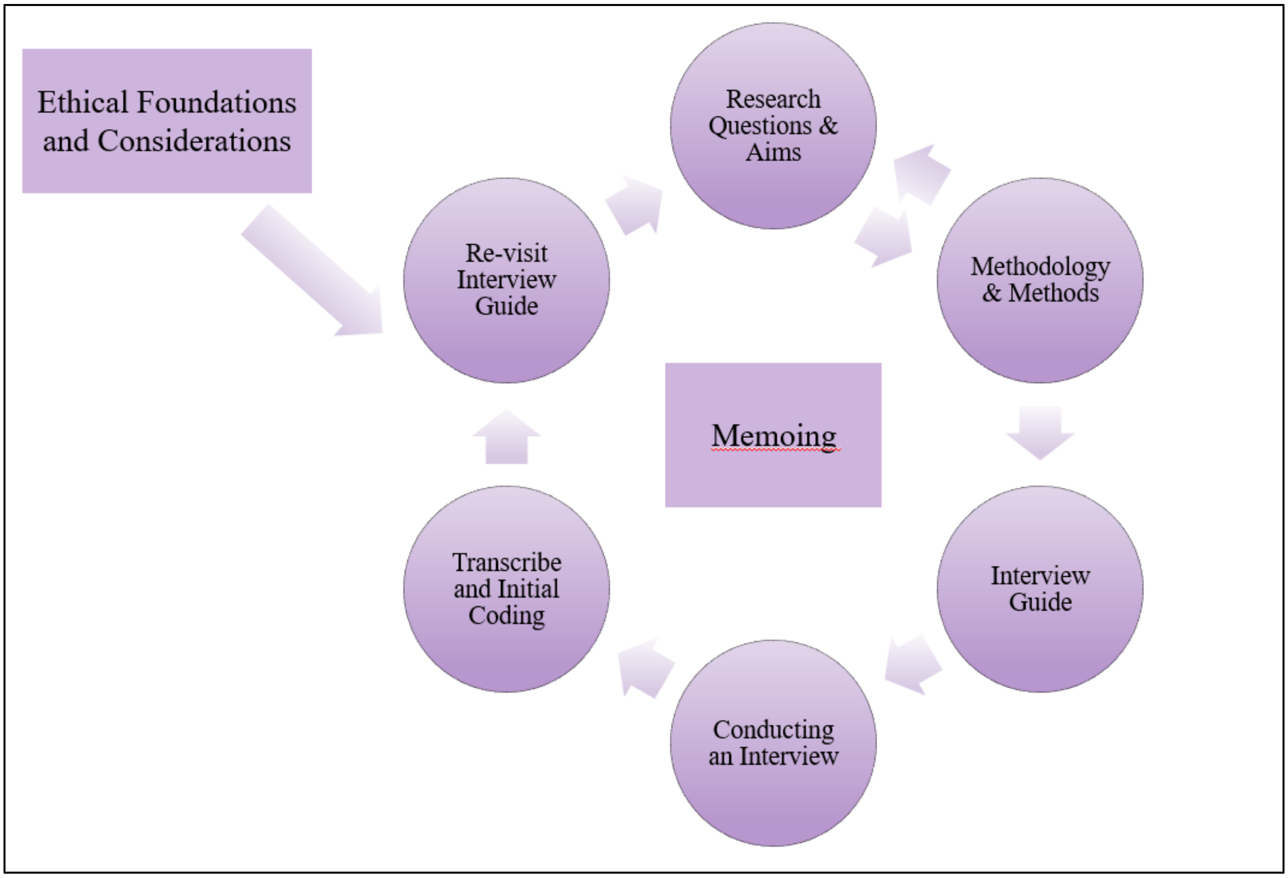


Figure 2.1. Illustration of Constructivist Grounded Theory Methodology. This figure shows the process for constructivist grounded theory that I deployed throughout this dissertation beginning with research questions and aims, moving through methods and methodology, interview guide, conducting interviews, transcription and initial coding, and re-visiting the interview guide with memoing and ethical foundations.

Figure 1 (pictured above) is a visualization depicting my process throughout this dissertation derived from the principles of constructivist grounded theory. Throughout this process, I utilized the principles of CGT in which research questions, aims, methodology, and methods all influence each other. Some researchers have argued that qualitative rigor and transparency occurs when epistemological stance, methodology, and methods are aligned which is the case for this dissertation (Carter & Little, 2007). My positionality as a researcher influenced the methodology which, in turn, influences the ways in which questions are asked of participants and what questions are asked in the interview guide. Additionally, I applied constructivist grounded theory principles to focus on understanding processes, theoretical sampling, and theoretical cores. This methodology is consistent with other qualitative methodologies in that it features open-ended questions which allows for narrative reflection from participants.

Throughout this dissertation and in constructivist grounded theory specifically, data collection and analysis are concurrent, meaning that both processes happen at the same time; data from interviews influences the interview guide and the overall research questions which allows space for change based on emerging data. This process has allowed me to see emerging facets of theoretical concepts, as well as shift or re-work interview questions and use theoretical sampling throughout the process of collecting and analyzing data. Lastly, ethical foundations and considerations underlie all aspects of this methodology and this dissertation overall.

The aims for this research were 1.) to examine direct care workers' experiences of work throughout the COVID-19 pandemic 2.) to understand how direct care workers navigate and utilize resources and support mechanisms 3.) to identify the processes in which direct care workers practice self-care. As I collected and coded the data, these research aims evolved and broadened. Furthermore, the research questions and the interview guide align with constructivist grounded theory in that they are aimed at understanding nuanced experiences of work throughout the COVID-19 pandemic for direct care workers.

Throughout this research, I have written extensive memos crucial to constructivist grounded theory methodology (Charmaz, 2014). Memo-writing has filled the gap between coding and writing results, acting as a place for reflection and expansion upon codes. I wrote memos after each interview and after each coding session. Memo-writing as a piece of the analytic process provided space for further reflection and theorizing and allowed me to stay close to the data. Through these memos, I thought and reflected about any issues arising with this research, literature which aligns or challenges my chosen methodology or epistemological stance, literature about my research topic(s), and my feelings related to this dissertation. In particular, memos also helped me process my feelings and experiences regarding this dissertation work.

III. Researcher Reflexivity

My epistemological stance is a part of researcher reflexivity and is important to constructivist grounded theory. My positionality as a researcher can heavily influence the research and discussion of such context is encouraged; a researcher's topic of interest, the questions they ask, how those questions are asked, methodologies chosen, data analysis, etc. are all influenced by the researcher's lived experiences. In other literature, the researcher is described as a tool, as the questions are shaped by the researcher and the data is co-constructed with the researcher and participants. In this section, I will discuss my approach for this dissertation as well as my own positionality.

The methodologies I employ throughout my research endeavors are influenced by my experiences growing up, as I value amplifying the voices of participants and co-constructing narratives/data. I am a first-generation college and now graduate student from a low socioeconomic status community, which is also considered medically underserved. Additionally, I identify as a white woman. My background and identity have influenced the types of topics I am interested in, including but not limited to socioeconomic status, inequality, aging, medically underserved communities, stigma, etc. The questions I ask in research (and of society in general) are also shaped by my identity and background.

My family and community spurred my interest in equity in aging and drives my commitment to a career in aging research. Growing up in New Hampshire in a HRSA-designated rural and CMMS-designated low income and health professional shortage area, health care was often hard to access. Further, both of my grandfathers suffered from Alzheimer’s disease for many years before passing away. It was difficult to access, travel to, and afford memory care services. These experiences sparked pressing questions that have set the course of my academic trajectory: what does it mean to age in society? How do inequalities impact the care that older adults receive? How is caregiving intertwined with emotional and physical labor? I grappled with these looming questions and, in doing so, became interested in the field of sociology for its theoretical and methodological applications in the study of inequality, stigma, and health disparities in aging.

I believe that biases are inherent in research and impossible to eliminate, thus it is important to disclose biases and positionality in a transparent way. In my research, I place a large emphasis on researcher reflexivity, positionality, and transparency which fits with the overall methodology of constructivist grounded theory (Charmaz, 2014). Specifically in this research, I seek to amplify the voices of direct care workers in new and innovative ways. Furthermore, I hope to address larger gaps in the literature and societal issues regarding aging, caregiving, and equity in meaningful ways. Additionally, I think that certain positionalities may even be beneficial to building rapport, gaining entrée, and garnering unique insights surrounding certain topics.

IV. Recruitment and Sampling

This dissertation deployed two types of sampling: 1) convenience sampling and 2) snowball sampling aiming to understand the experiences of direct care workers providing care and services for non-family members.

I first recruited participants through convenience sampling, contacting people already in my personal and professional networks that met eligibility criteria who may be interested in participating. Then I contacted home health and/or home care agencies across the United States via phone or email to distribute a flyer about this dissertation. Snowball sampling often occurred, wherein participants would contact co-workers, friends, and/or family members who also met eligibility criteria and may be interested in participating. Additionally, I created posts on social media platforms for recruitment purposes such as Facebook and Reddit with permission from moderators on forums.

I conducted semi-structured interviews on the phone with home care workers after screening for eligibility. Inclusion criteria included: adults aged 18 or older, live in the United States, work with older adults, work in individual homes and are paid for their labor (but can also hold other positions, such as in a nursing home or other occupation in general), primarily provided care and services to non-family members, and were comfortable speaking in English. To protect participants' anonymity, pseudonyms were used throughout this work. As illustrated in Figure 2, a participant flow chart, I reached 1,189 home care or home health agencies either by phone or email. 557 agreed to a secondary form of contact, either through email or by phone. Overall, 55 people were interested in participating in this research, 2 of which were ineligible according to exclusion criteria (they primarily provided care for children, not older adults), 10 did not complete an interview, and 45 completed an interview. Additionally, 2 interviews were excluded due to potential repeat interviews. Therefore, the final analytic sample was 43 interviews.

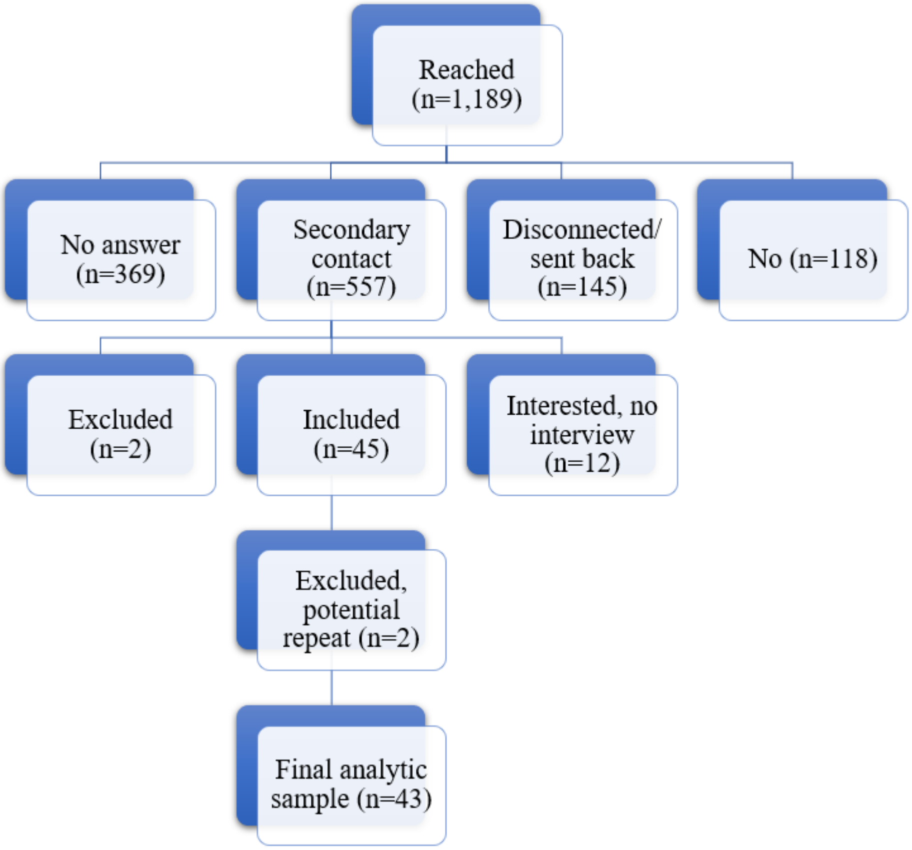


Figure 2.2 Participant flow chart. This flow chart shows that I reached 1,189 home health or home care agencies, and ended with a final analytic sample of 43 participants.

Participants were compensated for their time with a $40 e-gift card of their choice (Visa, Amazon, Walmart, etc.). Interviews consisted of open-ended questions about topics such as a typical day at work, caseload and work scheduling, sources of support, self-care techniques, experiences during the COVID-19 pandemic, relationships with clients and family members, experiences with managers or supervisors, and why they chose home care as a profession.

As this is a qualitative study, participants were asked about what identities were important to them and discussed in conversation. Some of these identities are reflected in the demographic tables in each chapter, which includes participants' pseudonyms, gender identity, racial identity, number of years spent caregiving, and number of clients when participants chose to share this information. The demographic tables vary per chapter, as they only reflect information for participants whose excerpts appear in each chapter. However, consistent with the literature, the majority of participants in this dissertation identified as women of color. In the overall sample, participants had between 6 months to over 40 years of experience in the care workforce. Participants had between 1 to 4 clients per week in the full analytic sample, which fluctuated for a variety of reasons such as client need and availability, clients passing away or discontinuing services, covering other shifts, etc.

V. Data Collection

In-Depth Interviews and Data Collection

One method deployed in this research is semi-structured in-depth interviewing. This research focuses on direct care workers' experiences of work throughout the COVID-19 pandemic while caring for older adults in the U.S. Interviews were conducted with adults aged 18 or older who live in the United States, work with older adults, and work as direct care workers and are paid for their labor (but can also hold other positions, such as in a nursing home or other occupation in general) as previously described. All interviews took place on the telephone.

After discussing the consent form and affirming consent verbally, interviews lasted between 20 minutes and one hour. Interviews consisted of open-ended questions, which were audio-recorded with permission and transcribed after obtaining participants' consent. Interview questions focused on narratives and storytelling related to experiences of work throughout the

COVID-19 pandemic. Additionally, I asked questions about experiences with discrimination and the ways in which identity (broadly) impacts their work. This study has been approved by the University of California, San Francisco (UCSF) Institutional Review Board (IRB). You can also find relevant material for the IRB application, including the flyer and interview guide, in the Appendix of this dissertation.

Another important aspect of constructivist grounded theory is reaching saturation. This occurs when researchers conduct interviews until no new "properties" emerge rather than no new patterns or themes, which is an important distinction that emphasizes nuanced experiences (Charmaz, 2014:213). There is much debate regarding an agreed-upon number of interviews for qualitative research that makes it 'valid' or 'good' or able to be published. Fitting with constructivist grounded theory methodology, I conducted interviews until saturation was reached, meaning that there are no new facets of theoretical categories. Saturation was reached at 43 total interviews.

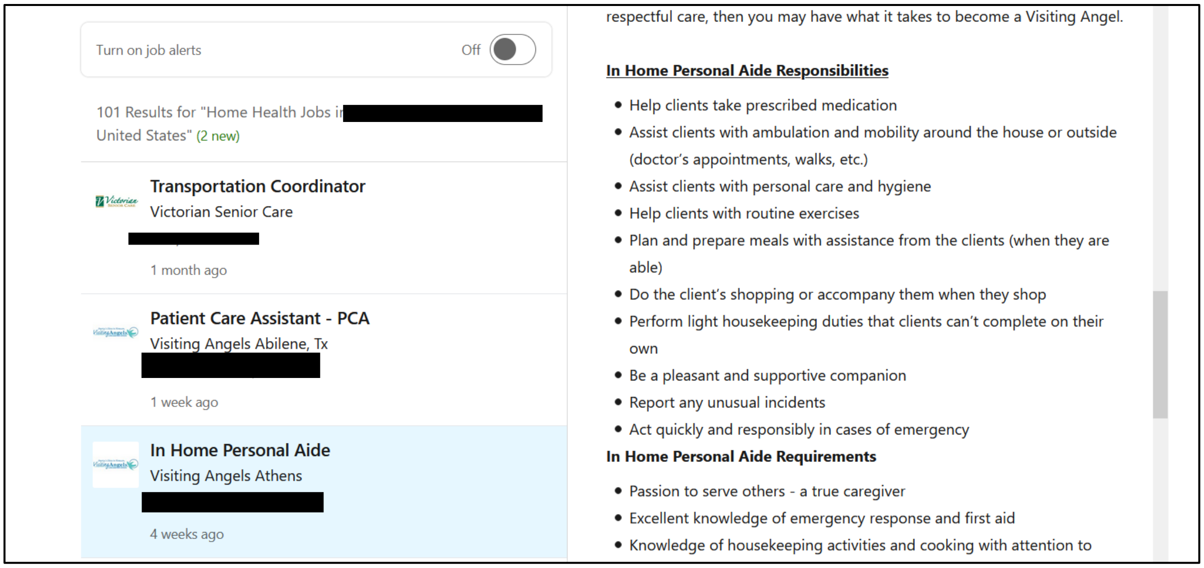
As I concurrently conducted interviews and analyzed and coded data, I regularly re-evaluated where to target my future recruitment given the emerging theories to further saturate and expand upon all facets of "core theoretical categories" (Charmaz, 2014: 213). This helped ensure data saturation, as this process helps to further explore all aspects of theoretical categories which emerge from the data. I performed two rounds of coding (initial and focused) to help identify the developing theoretical categories (please see data analysis section for more information on qualitative coding). Lastly, theoretical sampling allows for flexibility in recruitment from various avenues based on the data which helped to fulfill recruitment goals for this dissertation.

Collecting Data from Online Job Advertisements

In addition to in-depth interviewing, I used content analysis to examine online job advertisements for home health aides specifically. Analyzing job advertisements was illuminating regarding job requirements and expectations specific to emotional labor and feeling rules, such that they revealed expectations and/or constraints of emotional expression and highlighted emotion work in a different way. This data was publicly available on Indeed.com and contained pertinent information regarding emotional labor and feeling rules established by institutions (specifically, home health agencies).

In this quantitative analysis, I coded emotional labor as a binary variable, meaning that it was either required (1) or not (0) that indicated whether emotional labor was explicitly required in each job advertisement. As discussed in chapter 3, words and example phrases included in the category of emotional labor were: “interested in making a difference for older adults,” “sympathetic attitude,” “compassionate demeanor,” “meaning,” “giving back,” “empathy,” “sympathy,” “helping others,” “have a big heart,” “kindness,” “caring,” and “passion.”

More specifically, preliminary research on job advertisements for home health aides demonstrate that proscriptive statements about demeanor and emotional display are prominent. These job advertisements often list requirements regarding demeanor, attitude, or personality which constitutes feeling rules in the advertisement itself. I have inserted a screenshot to demonstrate this point; Figure 3 below is from a specific search in Indeed.com using the term “home health” and is specific to my regional area (though not associated or signed into an account). In this job advertisement, the company Visiting Angels states that prospective employees must “be pleasant” and “a true caregiver,” highlighting imposing rules regarding how one can act, feel, and express their emotions. These job advertisements provide additional insights and further contextualize caregivers' experiences of emotional labor whilst providing care and services to non-family older adults during the COVID-19 pandemic.



101 Results for "Home Health Jobs i[redacted] United States" (2 new)

Transportation Coordinator
Victorian Senior Care
[redacted]
1 month ago

Patient Care Assistant - PCA
Visiting Angels Abilene, Tx
[redacted]
1 week ago

In Home Personal Aide
Visiting Angels Athens
[redacted]
4 weeks ago

respectful care, then you may have what it takes to become a Visiting Angel.

In Home Personal Aide Responsibilities

- Help clients take prescribed medication
- Assist clients with ambulation and mobility around the house or outside (doctor's appointments, walks, etc.)
- Assist clients with personal care and hygiene
- Help clients with routine exercises
- Plan and prepare meals with assistance from the clients (when they are able)
- Do the client's shopping or accompany them when they shop
- Perform light housekeeping duties that clients can't complete on their own
- Be a pleasant and supportive companion
- Report any unusual incidents
- Act quickly and responsibly in cases of emergency

In Home Personal Aide Requirements

- Passion to serve others - a true caregiver
- Excellent knowledge of emergency response and first aid
- Knowledge of housekeeping activities and cooking with attention to

Figure 2.3: Screenshot of search. This is a screenshot of a search on Indeed.com, a common job listing website, which uses feeling rules to describe how home health aides should feel and act while providing care.

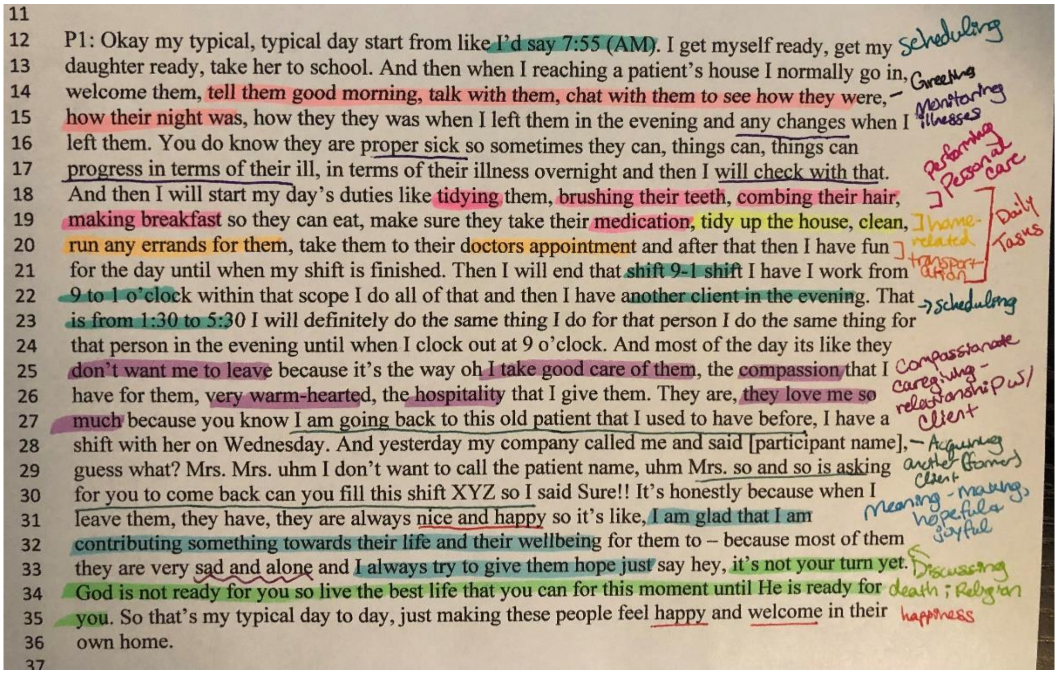
Using Indeed.com as a near nationally representative sample (in comparison to other job advertising websites), I selected 10 cities across the United States to collect data. These cities were chosen using randomizers online as well as regionally specific in order to ensure a more even distribution of cities across the U.S. I pulled all of the job advertisements for "home health aide" in each of the 10 cities which gave an analytic sample of (n=312) and input them into an excel spreadsheet for use in Stata, a data analysis software. To learn more about the specific cities and sizes and data cleaning, please see chapter three.

VI. Data Analysis

Data Analysis for In-Depth Interviews

Throughout this research, I used a coding software, NVivo, to help manage transcriptions and allow for cross-transcription analyses. Furthermore, I utilized hand-coding to assist in the data analysis process. With hand-coding, I color coded transcriptions and coded line-by-line, staying close to and engaged with the data. Hand-coding was primarily used in initial coding processes, although the majority of the coding (including focused coding) occurred using NVivo.

I engaged in two phases of coding consistent with CGT: 1) initial coding and 2) focused coding. Initial coding is the first phase of coding. In initial coding, I focused on coding actions rather than themes. This means that I used more words and phrases with gerunds and using "-ing" and stay away from simple descriptive language. Using active words allows me to stay more grounded in the data. Additionally, I did line-by-line coding in the initial phase of coding. I deployed hand coding in this phase of coding, using highlighters and colored pens to contribute to an initial codebook. Figure 4 below shows an example of a hand coded excerpt.



P1: Okay my typical, typical day start from like I'd say 7:55 (AM). I get myself ready, get my daughter ready, take her to school. And then when I reaching a patient's house I normally go in, welcome them, tell them good morning, talk with them, chat with them to see how they were, how their night was, how they they was when I left them in the evening and any changes when I left them. You do know they are proper sick so sometimes they can, things can, things can progress in terms of their ill, in terms of their illness overnight and then I will check with that. And then I will start my day's duties like tidying them, brushing their teeth, combing their hair, making breakfast so they can eat, make sure they take their medication, tidy up the house, clean, run any errands for them, take them to their doctors appointment and after that then I have fun for the day until when my shift is finished. Then I will end that shift 9-1 shift I have I work from 9 to 1 o'clock within that scope I do all of that and then I have another client in the evening. That is from 1:30 to 5:30 I will definitely do the same thing I do for that person I do the same thing for that person in the evening until when I clock out at 9 o'clock. And most of the day its like they don't want me to leave because it's the way oh I take good care of them, the compassion that I have for them, very warm-hearted, the hospitality that I give them. They are, they love me so much because you know I am going back to this old patient that I used to have before, I have a shift with her on Wednesday. And yesterday my company called me and said [participant name], guess what? Mrs. Mrs. uhm I don't want to call the patient name, uhm Mrs. so and so is asking for you to come back can you fill this shift XYZ so I said Sure!! It's honestly because when I leave them, they have, they are always nice and happy so it's like, I am glad that I am contributing something towards their life and their wellbeing for them to – because most of them they are very sad and alone and I always try to give them hope just say hey, it's not your turn yet. God is not ready for you so live the best life that you can for this moment until He is ready for you. So that's my typical day to day, just making these people feel happy and welcome in their own home.

Figure 2.4. Example of a hand coded excerpt from an interview transcript. It features different color-coding and descriptive text/analysis on the right side of the image.

Coding actions in the initial coding phase provides more focus on active theoretical processes rather than descriptions focusing on themes. Initial coding happened at the same time as conducting interviews and informed sampling, shifting interview questions, if necessary, etc. In this initial coding phase, I stayed close to the data and constructed an extensive codebook.

Focused coding is the second phase of coding in which I refined my initial codes and started analysis across multiple interviews. Part of focused coding also requires attention to words/phrases that have greater significance or occur more frequently across interviews. In focused coding, I did more theorizing and analysis across interviews rather than within them (the primary focus of the initial coding phase). I conducted focused coding via NVivo. In this phase of data analysis, I aimed to sharpen the codebook and analyze the data for processes regarding work for direct care workers.

Quantitative Analysis of Job Advertisements

I used Stata, a data analysis software, to perform linear probability regression models to understand the relationship between pay rates and emotional labor for home health aides. I also used MIT's Living Wage Calculator to determine the percentage of job advertisements that met living a living wage accounting for variances in geographic context. In this analysis, the dependent variable is the minimum/maximum wage listed in the job advertisements. The independent variables were all coded as dichotomous variables (required (1) or not (0): 1) emotional labor 2) certification or licensure requirements (Certified Nursing Assistant or Certified Home Health Aide) 3) a high school diploma (educational requirements) and 4) one year of experience providing care for older adults. For the written text in job advertisements, I coded with specific attention to words associated with emotional labor, which are listed in chapter 3. Charmaz explained that "grounded theories of documents can address form as well as content, audiences as well as authors, and production of the text as well as presentation of it" (Charmaz, 2014: 45). This quote suggests that analyzing not only the content of documents, but also their authors, may elucidate other insights about emotional labor for direct care workers, namely the ways in which institutions expect or require additional emotional labor.

Additionally, I wanted to explore whether and if so, how the relationship between pay rates and emotional labor changed if the data was stratified by agency size. I had contemplated, for example, if larger agencies might have more resources or finances to compensate for additional required emotional labor in comparison to smaller agencies. I created two subsets of the data based on home health agency size (small agencies 1,000 employees or fewer and large agencies 5,000-10,000 or more employees) to perform additional regression models. For more information about stratification and coding, please see chapter 3 for more information.

CHAPTER 3: HOME HEALTH AIDE JOB REQUIREMENTS AND PAY RATES

I. Introduction

In this chapter, I discuss the connection between the emotional demands of home health care jobs and their compensation through a quantitative content analysis of online job advertisements for home health aide positions (n=312). I found that in about 57% of the job advertisements, hourly wages were not sufficient to meet the living wage level according to the MIT Living Wage Calculator. Using linear probability models, I found that there is no statistically significant difference between pay rates listed by home health agencies requiring emotional labor and home health agencies not requiring emotional labor while holding education, experience, and licensure requirements constant. Stratifying the data by home health agency/company size (1,000 employees or less and 5,000 employees or more) yielded no statistically significant results. These findings support and expand upon existing literature that home health aides are undercompensated for their work regardless of agency size and provide evidence for the need for fair compensation and support.

In the United States, over 3.5 million home health aides provide care and assistance to older adults and people with disabilities living in the community (Almeida et al., 2021). These home health aides (HHAs) are disproportionately women of color whose labor is often invisible, undervalued, and undercompensated/underpaid presently and historically (Almeida et al 2021; Berry & Bell, 2012; Cranford, 2020; Loe, 2011; Laster Pirtle & Wright, 2021; PHI, 2018; Stacey, 2011). The median age for home health aides is 47 years old (PHI, 2018).

Home health aides provide essential labor in long-term care. Home health care is one of the fastest growing healthcare sectors and is expected to grow by 34% from 2019-2029 as the United States population ages and requires more care (Bureau of Labor Statistics, 2019-2020).

Research suggests that the majority of older adults (or 80%) live in the community rather than in long-term care facilities (Cohen & Tavares, 2021; Hudson, 2014), increasing demand for the growing and important home healthcare workforce.

Home health aides receive poor compensation for their work, demonstrated by low wages and minimal benefits such as health insurance, sick leave, and vacation time (Almeida et al., 2021; Boris & Klein, 2012; Cranford, 2020; Loe, 2011; Parks, 2003; Stacey, 2011). This work extends existing literature by comparing wages to a cost of living adjusted wage, which provides further insights about work for home care aides. A John A. Hartford Foundation poll and found that 73% of participants thought that direct care workers were underpaid, and leaders from home health agencies acknowledged the need for greater support and wages for home health aides in another study (John A. Hartford Foundation, 2022; Tsui et al., 2021). Consistent with this work, researchers found that home health aides providing care for older adults in New York City often were not compensated for the hours they worked (Shotwell et al., 2019). A meta-analysis of qualitative studies examining occupational health for home health aides found that the physically strenuous work, low wages, and lack of support from home health agencies negatively impacted their occupational health (Grasmo et al., 2021). These studies highlight the need for fair compensation and more support for home health aides.

Home health aides provide care and services for the physical, mental, emotional, and social health of millions of older adults living in the community. Importantly, these jobs also include/require a great deal of emotional labor, which occurs when home health aides manage their emotions at work according to institutional “feeling rules,” set either by home health agencies or individual clients for independent HHAs in consumer-directed programs (Hochschild, 1983). These “feeling rules” dictate what emotions are acceptable and when, as well as requiring or restricting behaviors and actions based on those feelings that are created, implemented, and enforced by larger institutions (Hochschild, 1983). This spurs the question, are home health aides paid extra in instances where emotional labor is required?

Literature suggests complex consequences of emotional labor. Some research, for example, highlights fictive kin relationships and reciprocal bonding between home health aides and clients. Fictive kin relationships are close bonds between a caregiver and client that are mutually beneficial. In these relationships, the caregiver becomes like family through the bond of providing care (Dodson and Zincavage, 2007; Karner, 1998; Stacey, 2011). Conversely, other research demonstrates significant negative consequences of emotional labor for caregivers, such as higher risk for stress, burnout, anxiety, depression, psychological distress, and earlier death (Hochschild, 1983; Jeung et al., 2018; Lopez, 2006; National Center on Caregiving, 2015; Stacey, 2011). Based on the literature, there may be more nuanced experiences and consequences as a result of emotional labor.

Using an analysis of job advertisements, this research examines the relationship between home health aides' wages and home health agencies' expectations of emotional labor. Quantitative data was collected from n=312 online job advertisements from 10 large cities in the United States. The use of quantitative data collected from job advertisements online allows for an understanding of occupational demands and compensation. I also coded narrative data to create a quantitative measure of emotion work requirements.

This study addresses three research questions: 1) What are the prevailing pay rates for home health aides and how do they compare to living wages? 2) What is the relationship between emotion work requirements and pay rates in home health aide job advertisements? 3) What happens to that relationship when stratified by home health agency size?

II. Methods

Data Collection

I used Indeed.com to gather job listings for home health aides in 10 randomized cities across the United States. Indeed is the largest online job posting site globally with over 250 million active users each month, over 4 times larger than Glassdoor and 10 times larger than ZipRecruiter (other job posting websites) (Glassdoor, 2022; Google Analytics, 2020; Persaud, 2021). I chose to use Indeed.com as a database because it was the most nationally representative given its size in comparison to similar job advertising websites.

The cities were chosen using randomizers online, and in some cases specified by region to ensure a more even distribution across the four main regions of the United States: the Northeast, the South, the Mid-West, and the West. The cities are listed here in alphabetical order: 1) Atlanta, Georgia 2) Austin, Texas 3) Boston, Massachusetts 4) Buffalo, New York 5) Chicago, Illinois 6) Cincinnati, Ohio 7) Denver, Colorado 8) Miami, Florida 9) Oakland, California 10) Portland, Oregon. The population sizes range from 278,349 (Buffalo) to about 2.7 million (Chicago), and the median population size is 575, 627. Table 1 below demonstrates the number of job advertisements in each city.

Table 3.1. List of cities. Descriptive list of number of job advertisements per city, using the 10 major cities featured in this dissertation.

	Number of Advertisements
City, State	
Atlanta, Georgia	24
Austin, Texas	27
Boston, Massachusetts	40
Buffalo, New York	23
Chicago, Illinois	40
Cincinnati, Ohio	38
Denver, Colorado	19
Miami, Florida	58
Oakland, California	18
Portland, Oregon	25

These job advertisements were collected during the 5-month time period from August to December 2021. I utilized the search term "home health aide" and specified by city to sharpen the search area geographically. Advertisements that were titled "personal care aide" as a similar occupation title were included in this data, though not specified in the search terms. I only included job advertisements in which home health aides provided care for older adults in the final analyses. Home health agencies posted most of these job advertisements, though individual people/clients looking for a home health aide posted a few as well.

I started with 331 job advertisements collected from the 10 cities. I eliminated 19 job advertisements for several reasons: 1) specified providing care for adults or children with disabilities (n=5) 2) duplicate postings, wherein Indeed.com listed the same advertisement more than once (n=7) 3) advertising for family caregivers in a consumer-directed personal-assistance program (n=1) 4) advertisements for hospice care providers (n=3) 5) seeking a "patient sitter" working in a hospital setting (n=1), and 6) an app or device client service provider (n=2). After eliminating these advertisements, 312 job postings across all 10 cities (n=312) remained. I excluded missing only for the final analysis when job listings did not include hourly pay rates which was 2.56% (n=8), and excluded live-in jobs (n=5, or 1.60%), with one job posting falling into both exclusion categories of missing pay and being live-in (n=1, or 0.32%) to total n=298.

Image 1 below is an example of a job advertisement on Indeed.com. In this advertisement, the pay rate is displayed as a pay range from $12-$13 an hour. Most job postings featured pay in this way, though a few had a singular hourly rate. This job advertisement also features qualifications, including both a driver's license and a CNA which is further expanded under the "skills" header including first aid training and a high school degree. Under the job description and responsibilities and skills headers, the agency specifies seeking someone with a "compassionate personality." This sample is representative of the advertisements I collected and analyzed. Here, I have redacted the name of the agency for confidentiality.

Home Health Aide (Atlanta 35hrs)

[redacted]

Atlanta, GA

$12 - $13 an hour - Full-time

Job details

Salary

$12 - $13 an hour

Specialties

Home Health

Available shifts

Day shift, Weekend availability, Monday to Friday

Job Type

Full-time

Qualifications

- Driver's License (Preferred)
- CNA (Preferred)

Full Job Description

We are looking for a compassionate Home Health Aide to provide assistance in daily living and personal care services in patients homes in accordance with an established care plan.

Responsibilities

- Provide health care services in patients residences
- Perform domestic and household tasks
- Transport and accompany patients to doctors office or to hospital
- Administer simple prescribed medications
- Assist with clients personal care activities
- Assist patients with mobility
- Provide companionship and basic emotional or psychological support

Skills

- Proven working experience as home health aide
- Familiarity with basic nutrition and personal hygiene standards
- Nursing and health care administration skills
- Caring and compassionate personality
- Current CPR certificate
- First Aid training
- Valid driver's license
- High school degree

Figure 3.2. Advertisement example. An example of a job advertisement on Indeed.com for a home health aide in Atlanta.

Coding

For quantitative analyses, the dependent variable is a dichotomous indicator of whether the wage is a living wage or not. Stata measured if the minimum pay for one adult was greater than the living wage in each city (1) or not (0) and whether the maximum pay was greater than the living wage in each city (1) or not (0) by individual job posting. I used MIT's Living Wage Calculator to establish the living wage threshold geographically. This shows the percentage of job postings that met the living wage threshold. Additionally, I coded job postings that did not list wages as missing and excluded from the final analysis (n=298). Any category that did not include information was coded into a category as not required.

There are four independent variables included in this analysis: emotional labor, certification or licensure requirements (Certified Nursing Assistant or Certified Home Health Aide), a high school diploma, and one year of experience providing care for older adults. Emotional labor was dichotomized into required (1) or not (0) based on qualitative/narrative data which indicated whether emotional labor was explicitly required in each job advertisement. All words and example phrases included in the category of emotional labor are: "interested in making a difference for older adults," "sympathetic attitude," "compassionate demeanor," "meaning," "giving back," "empathy," "sympathy," "helping others," "have a big heart," "kindness," "caring," and "passion." Overall, I found that 60% of all job advertisements required emotional labor.

Certification requirements were coded into a binary variable, required (1) or not required (0). High school diploma was also coded as a dichotomous variable, required (1) or not required (0). Lastly, having at least one year of prior experience was coded into a binary, required (1) or not required (0).

Additionally, I created two subsets of the data based on home health agency size to determine whether the relationship between emotion work and wages is different between small and large agencies. . I considered small agencies as 50-1,000 employees (n=105), and large agencies as 5,000-10,000 or more employees (n=74). I coded agency size as a dichotomous variable, small agency (0) and large agency (1). The remainder of entries were coded as missing if I could not find number of employees (n=133).

Data Analysis

In this research, I used Microsoft Excel, MIT's Living Wage Calculator, and Stata for data analysis. I utilized Microsoft Excel to help with data management and basic quantitative analyses. Additionally, I used MIT's Living Wage Calculator to better understand and contextualize hourly pay rates for home health aides geographically/regionally across the U.S. I used Stata, a quantitative analysis software, to perform linear probability regression models and understand the percentage of job postings that meet a living wage threshold defined by MIT's Living Wage Calculator.

III. Results

Description of Job Requirements and Hourly Pay Rates

Table 2 shows descriptive statistics regarding the percentage of job postings that required various certifications and experience level, as well as common job tasks and requirements for providing companionship.

Table 3.3. Descriptive frequency of qualifications and tasks. Descriptive frequency of qualifications and common job tasks, including qualifications such as licensure, driver's license, CRP certification, educational level, experience level, and common job tasks like personal care, light housekeeping, meal preparation, and companionship.

	Percentage of Job Postings
Qualifications	
CNA or CHHA	50%
Driver's license	48%
CPR certification	20%
High school diploma	44%
One year of experience (minimum)	50%
Common Job Tasks	
Personal care	71%
Light housekeeping	64%
Meal preparation	57%
Companionship	36%

Common licensure requirements include certification and training via a Certified Nursing Assistant (CNA) and/or Certified Home Health Aide (CHHA). Personal care was the most frequently listed job task, which includes helping clients with dressing, showering or bathing, using the restroom, hair and nail care, and dental care. Another common job task was light housekeeping, which involves laundry, dusting, washing dishes, and trash removal among other tasks.

After excluding job postings missing wages, I used Stata to determine the percentage of job advertisements that provide a living wage. In order to account for varying costs of living regionally, I used MIT's Living Wage Calculator, which "determine[s] a local wage rate that allows residents to meet minimum standards of living" to better contextualize the pay rates for home health aides (Glasmeier, 2022). As shown in Image 1, most job advertisements provide a pay range. To account for this pay range, I conduced two separate analyses to observe 1) the percentage of job postings in which the minimum wage meets the living wage level and 2) the percentage of job postings in which the maximum wage meets the living wage level according to the Living Wage Calculator. Table 3 shows the percentage of job advertisements that meet the living wage threshold for 1 adult, and for 1 adult and 1 child.

Table 3.4. Table noting what percentage of job postings meet a living wage. Percentage of job postings where wages meet the living wage threshold for one adult and one adult and one child.

	Percentage of Job Ads where Minimum Wage is Living Wage	Percentage of Job Ads where Maximum Wage is Living Wage
For 1 Adult	14.70%	43.13%
For 1 Adult and 1 Child	4.15%	4.15%

As illustrated in Table 3, the percentage of job advertisements where the minimum wage is the living wage for 1 adult is 14.70%, and 4.15% for one adult and one child. Additionally, the percentage of job advertisements where the maximum wage meets the living wage for one adult is 43.13% and 4.15% for one adult and one child. Even when using the maximum pay listed by the job advertisements, less than half of all job postings provided a living wage to home health aides for one adult. For one adult and one child, the maximum pay according to the job advertisements provided a living wage less than one twentieth of the time.

Does emotion work impact pay rates?

Because these job postings provide information for both pay rates and emotional requirements at work, I transformed emotional labor into a dichotomous variable to see whether it is associated with higher or lower wages. I conducted linear probability models using regression analyses for minimum and maximum wages as dependent variables and emotional labor, certifications, high school diploma, and experience level as independent variables (n=298).

Table 3.5. Regression models. Wage sufficiency regressed on job requirements (n=298) with two models.

	Model 1 Minimum Wage > Living Wage	Model 2 Maximum Wage > Living Wage
Emotional Labor	0.006	0.039
	(0.037)	(0.059)
Certification (CNA, CHHA)	0.018	0.049
	(0.037)	(0.059)
High School Diploma	0.060	0.029
	(0.038)	(0.061)
One Year of Experience	-0.005	0.050
	(0.038)	(0.060)

+ Note: Minimum wage is the low end of the advertised pay range and maximum wage is the high end of the pay range. The coefficients are from linear probability models and standard errors in parentheses.

Table 4 shows the separate regression analyses using the dependent variable pays living wage according to the job advertisements as dependent variables. Using linear probability models, Stata is predicting the probability that the dependent variable is 1; in this case, Stata is predicting the probability that the minimum wage (or maximum wage) meets the living wage level given the control variables, which in this case is training, education, and experience level.

First, looking at the minimum wage as the dependent variable, if the job advertisement required emotional labor the probability of the minimum wage meeting the living wage level is 0.006 greater than if there is no emotional labor holding all other variables constant. Now looking at the maximum wage as the dependent variable, if the job advertisement requires emotional labor the probability of the maximum wage meeting the living wage level is 0.039 greater than if there is no emotional labor holding all other variables constant. Further, none of the results were statistically significant for both regression models. This means that there is no statistically significant difference in the probability that pay exceeds the living wage when emotional labor is a job requirement.

Does emotion work impact pay rates when stratified by home health agency size?

After stratifying by home health agency size, I performed separate linear probability regression models using the same process described above to understand whether pay rates would differ while holding certifications, high school diploma, and experience level constant. Table 5 shows linear probability regression models.

Table 3.6. Regression models by agency size. Pays living wage regressed on job requirements stratified by size of agency, large agency (n=74) and small agency (n=105).

	Small Agency Model 1 Minimum Wage	Small Agency Model 2 Maximum Wage	Large Agency Model 3 Minimum Wage	Large Agency Model 4 Maximum Wage
Emotional Labor	0.006 (0.063)	0.089 (0.102)	0.028 (0.074)	0.104 (0.120)
Certification (CNA, CHHA)	0.063 (0.061)	0.177 (0.099)	0.011 (0.071)	0.089 (0.114)
High School Diploma	0.048 (0.066)	-0.025 (0.107)	0.045 (0.075)	0.201 (0.121)
One Year of Experience	-0.062 (0.064)	0.056 (0.103)	0.019 (0.074)	-0.143 (0.120)

+ Note: Minimum wage is the low end of the advertised pay range and maximum wage is the high end of the pay range. The coefficients are from linear probability models and standard errors in parentheses.

None of the four regression models were statistically significant. This means that even when stratifying by home health agency size, there is no statistically significant difference in probability of higher pay based on emotional labor requirements.

IV. Discussion & Conclusion

The purpose of this research is to explore home health aides' experiences of work by examining pay rates and institutional requirements for emotional labor. This research draws on n=312 job advertisements to explore 1) percentage of job advertisements with minimum and maximum pay that meet the living wage level 2) the relationship between emotional labor requirements and pay rates and 3) whether that relationship changed or differed based on stratification of home health agency size.

This research demonstrates that home health aides are severely underpaid, especially when considering pay rates according to job postings in comparison with a living wage utilizing MIT's Living Wage Calculator. This research demonstrates that minimum wages present in job postings were not enough to provide a living wage for one adult with no children. Furthermore, for one adult and one child, the maximum wage level did not meet the living wage level in over 95% of the job postings. This concurs and expands upon the current literature that home health aides are undercompensated for their work despite being considered essential frontline workers and a part of the healthcare team (Almeida et al., 2021; Loe, 2011).

Interestingly, this research suggests that there was no statistically significant difference in pay rates for home health agencies that explicitly required emotional labor and those that did not. Overall, this demonstrates that home health aides' emotional labor is undercompensated. This is a noteworthy finding, and consistent with the contention that home health aides are required to do emotional labor and yet are not compensated for complex and often-draining work demands (Almeida et al., 2021; Boris & Klein, 2012; Cranford, 2020; Loe, 2011; Stacey, 2011).

This research explores pay rates and expectations about emotional labor for home health aides. This work has implications for raising pay rates for home health aides, and offering other support mechanisms to reduce burnout, turnover, and other potential negative consequences of emotional labor. This research is timely and important, as home health aides are vital in our long-term care system. As the United States population continues to grow older, and the demand for home health care continues to increase, it is imperative to critically examine pay rates and institutional requirements for emotional labor for home health aides in order to raise pay rates and offer more support for home health aides.

Limitations

There are a few limitations to this study. First, this analysis only examined job advertisements in large cities. Though this is a significant amount of data, enough to be generalizable to other large U.S. cities, it does not take into account home health aides' experiences in smaller cities or more rural spaces. Future work should highlight job advertisements for home health aides in rural spaces, which may be more limited in quantity in online spaces. Second, literature suggests that many home health aides and care providers often have more than one job, which is beyond the scope of this analysis. Lastly, exploring home health aides' experiences of work through qualitative analyses can help to understand more nuanced processes and experiences and should be examined in future research.

Conclusion

Home health aides are essential members of the healthcare team, and the home health care industry is growing and in high demand. By examining job advertisements using content analysis, this research supports the literature that home health aides are underpaid for their work. Furthermore, this research suggests that home health aides required to participate in emotional labor and not fairly compensated for this additional labor. As the demand for home health care continues to grow, it is imperative to provide a living wage for home health aides and to fairly compensate them for their work, as well as offer support mechanisms to minimize the potential negative consequences of emotional labor.

CHAPTER 4: BLURRING BOUNDARIES

I. Introduction

In this chapter, I argue that participants' intrinsic motivations for entering the direct care workforce create pathways and opportunities for both reciprocal, close relationships with clients and exploitation at an institutional and interpersonal level. Drawing on (n=43) in-depth interviews, I found that direct care workers often experienced blurring boundaries, also called role conflict or role ambiguity in other research, moving between personal and professional boundaries and spaces through their work. The unique care setting of individual homes coupled with intrinsic motivations for participation in the direct care workforce contribute to this boundary blurring and opens opportunities for reciprocal relationships with clients and also for exploitation at institutional and individual levels.

Over 4.8 million direct care workers are critical to the long-term care system, providing care and services to older adults and people living with disabilities in the United States (PHI, 2023). Direct care work in individual homes is a fast-growing occupation, especially as the demand for home and community-based services continues to rise (Bureau of Labor Statistics, 2019-2020). Direct care workers providing care and services in individual homes often form close, reciprocal relationships with clients, and yet also face challenges such as blurring personal and professional boundaries.

Direct care workers providing care and services in individual homes specifically may face challenges arising from the environmental setting of work, such as occupational hazards as well as lack of supervision via the one-on-one nature of this work, yet also have a unique position to form close reciprocal relationships with clients. For example, one qualitative study with home care workers as well as union and insurance representatives suggested that occupational hazards included various physical and psychosocial aspects, such as back and shoulder issues, violence and abuse, fall/slip hazards, poor air quality, and animals in the home (Markkanan et al., 2013). However, some research suggests that positive relationships with clients and feelings of satisfaction as a result of this "rewarding" work may be protective of occupational health (Grasmo, Liaset, & Redzovic, 2021). Another more recent qualitative study with home care aides, clients, and managers noted that "address[ing] the safety of both clients and aides can influence home care job satisfaction and retention," (Brouillette et al., 2023:571). Here, it is evident that the setting of care and services in individual homes creates a space ripe for closeness with clients and also potential hazards/challenges that have implications for worker safety and retention.

Additionally, direct care workers often form close reciprocal relationships with their clients. Also known as fictive kin, these relationships are often reciprocal and valued by clients and direct care workers alike. Karner (1998) noted that folks with fictive kin relationships "***provide care like family*** and ***do what family does,***" with other research suggesting that direct care workers are treated like family by clients and all parties value their relationship especially in terms of social support (Almeida, Cohen, Stone, & Weller, 2021; Aronson & Neysmith, 1996; Stacey, 2011). Direct care workers in home care settings often experience reciprocal relationships with clients especially given the amount of time spent within the individual home, the frequency of visits, and the intimate nature of many tasks part of this work. For example, one study with home care aides in the U.S. stated that "aides reported that their daily intimate personal care tasks such as showering, bathing, and toileting contribute to swift bonding with the client." (Markkanan et al., 2013: 447-448). This concept is important to understand, as I draw on this information to show how direct care workers often form these close relationships with clients which may result in challenges at work such as performing or feeling pressure to perform additional labor.

Close relationships between care workers and clients are often beneficial and perceived as important for improving and upholding the quality of person-centered care for older adults, yet may often complicate personal and professional boundaries. In one study, researchers conducted qualitative interviews with dyads of home health aides and their clients which demonstrated that they form close relationships that are beneficial for all parties (Piercy, 2000). Furthermore, other research notes that "aides reported that respectful relationships with clients and familiarity from years of experience in long-term working relationships with clients make their jobs easier" and clients also noted companionship as "one of the best aspects of home care" (Brouillette et al., 2023:576). However, researchers have also found that paid care workers in the home occupy an "ambiguous position described by informants as a liminal status, which is characterized by the ambiguity of being 'betwixt and between' two culturally defined social positions," of family and professionals, meaning that they are sometimes perceived and constructed as family members and at times are not perceived or constructed as family (Barnhart, Huff, and Cotte, 2014:1686). This is often described as role conflict, which "may occur because home care work takes place in an environment which assumes a dual function: it is a person's home and a place of work" (Denton, Zeytinoğlu, & Davies, 2002:5).

There are many competing tensions in this kind of care work, such as navigating boundaries when providing professional care and services while also in someone's home setting, forming a relationship that is seen as integral to good person-centered care, and yet receiving societal and institutional messages and expectations about professionality such as not getting "too close" to clients (Mears, 2009). Navigating these boundaries and expectations can be difficult, often resulting in blurring professional and personal boundaries. Researchers often phrase this as role conflict or role ambiguity, and often focus on tension around personal and professional boundaries. For example, in research with caregivers in Australia, Mears and Watson articulate this relationship as “a “professional” relationship based in a “familial” context.” (Mears & Watson:153).

In a different but related work, Mears describes this tension further stating “care workers are constantly negotiating the boundaries between work relationships and personal relationships or friendships. These are fraught negotiations with constant merging, clashes and overlaps of personal/private lives with work/public lives” (Mears, 2009:155). This notion of personal and professional tension is reflected in other research as well, such as a qualitative study based in the United Kingdom which explained that “juggling the need to portray both compassion and professionality appeared to make it difficult for a home-care worker to keep a degree of personal distance between their work and personal life” (Abrams, et al., 2019: 1993). Other researchers further explained that this work is “guided by notions of professional confidentiality and professional practice and on the other hand driven by affective bonds of friendship” (Brink, 1989:5), noting that home care workers increasingly need to navigate “managing the potential dual role of ‘support worker’ and ‘friend,’” (Lam & Baxter, 2023:581). It is important to explore this lack of clarity regarding what constitutes professional and personal that may shift socially and spatially.

This blurring of the personal and professional boundaries often resulted in a variety of consequences for participants in research, such as stretching boundaries and performing additional labor outside of requirements by the agency. For example, in a large mixed-methods study of home care aides, researchers found that home care aides were regularly asked to perform tasks outside of their job requirements by clients or clients' family members, which was reflected in other studies as well (Karlsson et al., 2019). This is supported by other qualitative work, such that home care workers were asked to perform additional work tasks that "often resulted in boundaries being blurred" including "stay[ing] beyond their contracted hours to assist with jobs and build relationships with clients or even their families" (Abrams et al., 2019:1989). Other research adds more complexity here, suggesting that clients' family members could provide "complimentary labor" by providing additional support to workers, yet also could engage in "disrupted labor" patterns wherein family members heighted emotional or additional work tasks (Sims-Gould, Byrne, Tong, & Martin-Matthews, 2015). Blurring boundaries may also have implications for occupational safety and worker retention, as research found that home care "aides who reported receiving such task requests were more likely to report verbal and physical abuse and injury or pain on the job. They were slightly less likely to plan to stay on the job or recommend it to a friend." (Karlsson et al., 2019:372).

Researchers argue for notions of more fluid and flexible boundaries in home care settings guided by support from peers, supervisors, and their organization/agency which may positively impact quality of care and health outcomes for this workforce. In a study with home care workers and managers providing care and services for people living with dementia at the end of life, researchers stated that "given that the home-care workforce is increasingly involved in the provision of care to people with dementia, providing person-centered care may require increased flexibility in order to meet complex care needs" (Abrams et al., 2019:1978). This work argues for recognizing boundaries as more fluid, nuanced, and complex in-home care settings, particularly with clients living with dementia. Other researchers note that "firm, carefully laid down rules, across the board, did not necessarily work; and, indeed, all the workers spoke of some inevitable and (what they saw as) reasonable breaches of the rules" in home care settings (Mears & Watson, 2008:152-153). Further research shows that having peer support as well as organizational support is associated with better health outcomes for home care workers (Denton, Zeytinoğlu, Davies). Lastly, research suggests that "employer support, training, care plans, and feeling part of a care team can help aides navigate professional boundaries while delivering high quality care" (Karlsson, 2019:368).

In this work, I explore these tensions and blurring boundaries and contribute to the limited literature on this topic. Implications from this 1) support existing literature in naming these tensions and 2) enable home care/home health agencies to better support direct care workers in navigating these fluid boundaries through discussions with supervisors, peer-support groups, and training programs. For example, instead of outright discouraging close relationships with clients, this work can illuminate the complexities of reciprocal relationships and enable direct care workers to navigate personal and professional boundaries depending on their situation with support from their peers and agencies. I draw on 43 (n=43) semi-structured qualitative interviews with direct care workers providing care and services in home care settings for older adult non-family members in the United States. Given the often deeply personal ties to this work and the close relationships with clients, direct care workers often experienced blurring boundaries between the professional and personal, which created unique challenges aligning with the literature such as additional labor, hesitancy to be away from clients, and challenges creating or upholding these boundaries. Direct care workers occupy a unique space in their roles, perceived and treated at times as family members, which requires new perspectives on the fluidity of boundaries for this critical workforce.

II. Methods

The method deployed throughout this article (and a portion of the overall dissertation) was semi-structured qualitative interviews guided by constructivist grounded theory (GCT) (Charmaz, 2014). Overall, the analytic sample consists of 43 (n=43) interviews over the phone with direct care workers paid for their labor who primarily provide care and services to non-family older adults in the United States. For more broad information about constructivist grounded theory, please see chapter 2 focused on methods. There is additional information about my positionality, the role of memoing, recruitment processes and sample population, and data collection and analysis in chapter 2 as well.

Table 1 below shows some demographic information for participants whose narrative interview data appear in this chapter using pseudonyms. Consistent with the literature and overall sample, the majority of participants in this smaller group identified as women of color. Additionally, for this particular group, participants had between six months and over 40 years of experience in the direct careworkforce. On average for this group, participants had about 2 clients per week.

Table 4.1. Demographic table chapter four. Demographic information (gender identity, racial identity, years caregiving, and number of clients) for participants whose excerpts appear in this manuscript (n=10, overall sample n=43).

	Gender Identity	Racial Identity	Years Caregiving	Number of Clients
Veronica	Female	Preferred not to say	Preferred not to say	1-2 clients per week
Pauline	Female	White or Caucasian	30 years	3-4 clients per week
Aubree	Female	Black or African American	Preferred not to say	3-4 clients per week
Cami	Female	Black or African American	20 years	Preferred not to say
Celeste	Female	Black or African American	2 years	4 clients per week
Jenny	Female	Preferred not to say	0-3 years	1-2 clients per week
Jessica	Female	Honduran	8 years	1 client per week
Cynthia	Female	Black or African American	40+ years	2-4 clients per week
Margaret	Female	Preferred not to say	7 years	Preferred not to say
Isabel	Female	Preferred not to say	10+ years	2 clients per week
Robin	Female	Jamaican	2 years	2-3 clients per week

III. Findings

Intrinsic Motivations for Joining the Direct Care Workforce

Direct care workers explained why they chose home care as their work, many of which discussed helping others and giving back. When asked what led them to work in this field, most participants told me about how they wanted to help people driven by witnessing caregiving and/or death of family members, or familial experience with caregiving. Exploring why direct care workers for non-family members entered this workforce adds context and highlights their often deep roots in this field of work that makes it "more than a job."

The following excerpt is a typical case that reflect how parents, grandparents, or other family members were involved in caregiving or working in care settings that influenced participants' decisions to enter the direct care workforce.

> *So I come from a long line of caregivers. My mom, my grandmother, my aunt, they were all in the field of caregiving. It's something that I always wanted to do, I felt like I was driven to do it. I've actually went to school to try to become a nurse. I failed the test twice by a point, 2 points and I said you know there's got to be other things out there for me that have to do with direct contact. And so I ended up working in fields all my life that you know involved working with the elderly or working with children and things like that. I've always enjoyed it. I've always felt like I was driven to make a difference, to help people.* – Pauline

Several generations of Pauline's family were involved in the caregiving field. She explained that she felt "driven to make a difference," and sought out opportunities for "direct contact" with clients such as in nursing and direct care work. Other participants entered the direct care workforce largely due to volunteerism. For example, Cynthia's entrance to care work was rooted in volunteerism and spending time with her grandfather working in a hospital. This case further extends on notions regarding familial connections to the direct care field, as it is slightly different from the majority of participants' experiences. When asked to explain what drew her to care work, Cynthia reflected:

> *When I was in middle school I volunteered at the hospital. I amassed over 4800 volunteer hours from the 8th grade to the 12th grade. I would go in on Saturday, Sunday, and work 4 or 5 hours on the weekends and then in the summer months of course when we were out of school more. So I was very drawn to it from that point. My grandfather was the head of maintenance at the hospital that I worked at and I loved being there with my grandfather. So what happened was I'm working at the hospital and a lady asked me, she said "do you think you could come and help me out at home once I get home?" And I said "sure, I'll come and help you." And actually while I was in the hospital the people that did all the bed changing and cleaning up, they kind of trained me and I watched what they were doing when taking care of someone that was in the hospital. Anyway, so the one lady asked me to come and I would go for a couple of hours in the afternoon just basically standing by while she took a shower and make sure she took her medications. And I just took to it, from the 8th grade until now you know, 50 something years ago.* – Cynthia

Volunteering in a hospital at a young age presented Cynthia with an opportunity for direct care work in individual homes. She learned from her grandfather and other hospital staff how to take care of people and eventually joined the direct care workforce as a result of her early experiences. Volunteerism was an entry point into the care work sphere, and eventually into the direct care workforce for these participants.

Another common experience was that participants were present for care work or the death of a family member which ultimately drew them to this work. One participant, Pauline, noted that she lost her grandparents as a teenager and "always felt like I was so in awe of the care that they were given by the nurses and aides." Other direct care workers explained that they watched the care given to sick family members as well which drew them to home care. Margaret shared her experiences as a child when her mother had cancer:

> *I originally got into this field of work, when I was a child my mom had cancer. Thankfully she had a positive outcome. It took 3 years for her to fully get out of recovery from breast cancer. And I think what really inspired me to be in healthcare was just what was given to our family during the time that she was sick. We spent Christmases in the hospital with her. I still have it actually, a nurse had given me this tiny little teddy bear, she probably grabbed it on her way to work at the gas station or something. I was six years old and just, the idea that someone thought about my family in the times like that, it wasn't a great time. I always wanted to give that back to people, I wanted to give back the feeling of what I've experienced and then really what's kind of kept me in healthcare for this long was I watched my grandfather pass away in 2016 and I was very involved in his love and care. And after he passed my grandmother got diagnosed with cancer and she's still going but definitely on borrowed time…I think I got into healthcare more because I just wanted to give back what I feel like I've been given my whole life…I think about healthcare and my thought is, I don't think you should do it if you haven't lived part of it before. You have to know how to be a patient and a caregiver as well.* – Margaret

Margaret's childhood experiences with her mother's cancer diagnosis and treatment spurred her interest in giving back the kindness and compassion that care workers had given her family. Margaret was involved in her grandfather's care until his death which continued to deepen her passion for direct care work. Here, we see that these deep intrinsic and personal motivations create opportunities to develop close relationships with clients on the one hand, and space for exploitation on the other hand. Many direct care workers I spoke with witnessed care work and/or the deaths of their family or friends that spurred their interest in the direct care workforce. For Jenny pursuing work as a direct care worker and helping others gives back to the community. She stated:

> *What being a home caregiver means to me it means I feel helpful I feel useful that I am you know using my time to uhm facilitate another person just you know with their life and it means the world to me. I know that one day we all, well we don't all get to be that age, sometimes you know unfortunate things happen and younger people pass but I know that if I get to that age I am probably going to be needing assistance some care some help. And I just feel like it's kind of just giving, kind of like good karma [laughs] helping and then like oh maybe in the future when I need it I can remember like I did something and like it's coming back and feel a bit good about that. – Jenny*

For Jenny and others, they expressed that direct care work was giving back to others and positively impacting others' lives. Another common notion among these participants was that this work was a calling, that it was more than a job. Celeste explained:

> *I was really close to my grandmother and after she died I wanted to help the elderly. That was the main focus. And then once she died I would take her [another client] to her appointments and it was like I was trying to fill the hole in my heart basically…I feel like this is my calling. Even though I am a nurse, I knew I wanted to be more than a nurse …So with this it gives me it gives me like a new meaning of life. I can get to learn about the client I can get to learn their family, I get to be more open with them. And I can cook for them, do their nails, be there for them like I wish somebody was there for my grandmother. But it was only me with her.* – Celeste

Celeste's experience has many threads, such as her presence for the death of her grandmother and feeling this line of work was a calling and, was more than a job. As the owner of her own home care company, she was able to create "new meaning" through this work providing care and services to non-family older adults.

In this section, it is evident that direct care workers are more susceptible to blurring boundaries given that their deeply personal and intrinsic motivations for joining the workforce that creates opportunities for reciprocal or family like relationships and also create spaces for exploitation. The next section details ways in which these blurred boundaries create challenges for direct care workers in individual home settings, such as performing or feeling pressure to perform additional labor and hesitancy to be away from clients.

Blurring Personal and Professional Boundaries – Additional Labor

Because of direct care workers' close relationships with their clients, they often face challenges with blurring professional and personal boundaries and occupy a unique space in individuals' homes. One way in which this manifests is when direct care workers do additional labor/ unpaid work for clients or clients' families because they care about them and also at times are frustrated with this situation. For example, Jessica said:

> *One lady [client] wanted a special food, like seafood. I can't do that. And I said you know I can do the regular food. I have four children and I can cook the normal food, I'm not a chef, I can't do that the special food. And she got mad with me. That's the only thing, sometimes they think you can cook dishes they want. I try. I try, but I don't know if they like it or not.* – Jessica

Jessica noted how she tried to cook special meals based on clients' requests even though that extended over the boundaries of her job. Similarly, Cynthia expressed how she did additional cleaning around the house and cleaning dishes for family members of her client that was beyond her work requirements/professional boundaries. She stated:

> *She [client] had a housekeeper that used to come there for 16 years and when COVID hit she pulled out and never looked back. So here we are cleaning the house, you know. We're cleaning the house, the whole house…But its already laid out that no we don't do windows and no housekeeping or pulling out the vacuum cleaner no we're not doing that…Now we have had family members that start piling dishes up in the sink and never look back like we're supposed to do it. That could be very uncomfortable to deal with, could you wash your own dishes? I didn't come here to take care of you I came here to*

> *take care of your mom. I take care of her dishes, they're put away or in the dishwasher or whatever. You need to take care of your own dishes. So we have had struggles with that at times when family members come in there and make a mess and think that you're gonna clean it up*. – Cynthia

Cynthia explained how despite clear work boundaries of no additional housework, she engaged in more cleaning to help her client that extended beyond her regular job description. In this excerpt, Cynthia also discussed how sometimes family members expected her to do additional tasks for the entire household, not just her client, such as additional dishes. This additional work for the entire family was also reflected in Aubree's experiences. Aubree said:

> *The [client] that I'm at today, her family is always here so sometimes that's a good thing but a lot of times that's a bad thing because their families expect you to do for them as well. I have to let them know that I am strictly here for my client and my client only which makes it hard because they want you to wash dishes or they want you to clean up and then it's like I don't mind but I am only here to help my client because that's who needs the help. Like for instance like when I'm washing my client's clothes everybody's clothes is mixed in with hers so then they expect me to wash everybody's clothes. Everybody expects me to be there for them as well just because they are in the household* – Aubree

Aubree reflected on how often family members of clients expected her to do additional work. Cynthia and Aubree both discussed pressure to wash dishes for the entire household, which extended beyond job requirements and expectations. Aubree felt like she had to engage in other additional household tasks outside the purview of her job description, such as laundry and cleaning. Although less common, Cami explained how she was asked to train other direct care workers without pay. She stated:

> *I am training people, sometimes I am training somebody for a shift and I'm like I didn't get training for 5 hours. But why I gotta train somebody for 5 hours then, you know? [Laughs.] No, I don't [get paid for that]. Of course I want to get paid, like yeah I mean brain work is, why should I not get paid for it? That's my skill, I am good at it so it's just like, if I am going to be training somebody and that is going to be beneficial to the agency why should I not get paid? Even though we do it because we care at the end of the day there is money involved. Why am I training somebody that's gonna be beneficial to y'all [agency] when y'all gonna get more clients because you have an extra worker but then the training gotta come from me for free? But then you know down the line y'all*

> *gonna be benefitting, the state gonna be paying the agency money to care for that client so why shouldn't I get paid too for that time?* – Cami

Here, Cami explained how she often trained other people but was not paid for her time to do so by the agency, also known as wage theft. This additional labor is at the institutional level, rather than between direct care worker and client like in the previous examples. She noted how the agency would benefit from her training people for free. Cami also said that she genuinely cares for her clients and highlighted the for-profit system at her agency. It is evident that Cami engaged in work beyond her job expectations to train other employees and yet was not paid for this work.

Hesitancy Leaving their Clients

Direct care workers explained how taking time off from work was difficult or would work while sick because they were concerned about their clients, what they would think and how they would feel. Veronica detailed a close relationship with a client and felt like taking time off would be problematic:

> *There was one of my patients, she actually was not able to speak and not able to hear. So I used to work with her. It was difficult for me to explain to her but then after a few days of working with her I really felt so good staying with her. I felt like if I take off it's gonna be a problem because she might not like it. Or she may think that maybe I don't want to work with her or something. Because she was really friendly. Like even though she was not able to hear me as well as she was not able to speak, but I was still able to communicate with her you know. So that was a really special bond.* – Veronica

Veronica explained a particularly close relationship with one of her clients and how she felt that it would be difficult for her to take time off or to switch clients entirely given the close bond with her client. In a similar way, Aubree, that we heard from earlier, stated:

> *Yes I actually give them [clients] the ok to call me after hours if they need to talk about something or they need to go somewhere. Because you know sometimes they don't*

> *actually have transportation so you know I assist, I like to have a helping hand for them.* – Aubree

Aubree explained that she gives clients her phone number to call "after hours" presumably after work hours so she can give continued assistance to her clients. Aubree explained that she sometimes assisted clients with things after hours, such as transportation specifically, although this is outside of the expectations/requirements at the agency. Here, we see that personal and professional boundaries become blurred when Aubree engages in additional unpaid labor to continue providing care and assistance to her clients.

In addition to performing tasks beyond the scope of their work, some direct care workers faced more emotional challenges that permeated their personal lives as well. Robin noted how some clients do not want her to leave, which could be emotionally challenging to navigate, and how she missed her daughter's birthday while preparing her client for a big event. Robin said:

> *And most of the day it's like they don't want me to leave because it's the way I take good care of them, the compassion that I have for them, very warm-hearted, the hospitality that I give them…[One client], her grandson was going to play in a band at school. And I was telling her about "why you don't go?" and she said "no I don't want to go." Because she feels that she is so sick in her wheelchair she can't be going. I said to her no you are going to go…She said how? And I said I am gonna make it happen. And I did things on her behalf, I said get this car that can lift her wheelchair, I can make sure that she's dressed very nice and pretty and so forth…That day it was my daughter's birthday, my daughter's birthday. She turned 16 and it was her birthday that day…And she [client] went. And see she's not here today. So at least she got to witness that moment in her life with her grandchild before she passed this world. And I know she has that memory in her when she died…it sometimes takes up my personal life or, I try to work around it for the benefit of these patients. They need me, they need me. Although I know that I am a mother of 2 and a grandmother and a wife at the same time. But my husband understands that, my daughter understands that mom has to work because people depend on us.* – Robin

Robin noted how her clients didn't want her to leave which may be difficult, add further complexities, and continue to blur personal and professional boundaries. Here, she recalled a time when she helped her client prepare for an important event on the same evening as her own daughter's birthday party and noted her family's understanding about how working as a direct care worker sometimes impacted their non-work/personal lives. Isabel also expressed conflicting emotions about wanting to be present for her clients while also wanting to be present for herself and her family. She explained:

> *I do need to make more time for myself, I just gotta make the time, I got to be better with trying to do more for myself. I just feel bad I want to be there for my clients but you know I got to, you know I have family too and I need to realize that.* – Isabel

Isabel explained that she wanted to make more time for herself while at the same time expressing the importance of being present for her clients. This tension arising from blurring boundaries was common among these participants and highlights the ways in which direct care workers tried to navigate and name these sometimes conflicting roles.

IV. Discussion and Conclusion

In this research, I highlighted an under-explored tension wherein intrinsic and personal motivations for entering the direct care workforce open opportunities for deeply personal relationships with clients while also opening spaces for exploitation. Intrinsic motivations for entering the direct care workforce for participants included familial ties to the care work field, wanting to give back to the community, and witnessing the death or care work of a family member or friend. This aligns with the literature, with one study in Australia noting that people entered the care workforce because they wanted to give back and "make a difference" in the community (Mears & Watson, 2008:151). However, this work highlights new facets of these intrinsic motivations drawing folks to the direct care workforce in the ways that they open opportunities for both reciprocal and exploitative relationships. Because of their deep-rooted desire to do care work, direct care workers I spoke with often engaged in work beyond their regular requirements and resulted in blurring personal and professional boundaries. In this way, there was a direct connection between the intrinsic motivations for working as direct care workers which often resulted in selfless caregiving, and the exploitation apparent at the institutional and event client level.

This research suggests that direct care workers experience challenges as a result of blurred personal/professional boundaries and occupying a space in which they are perceived and treated as family and also as non-family which manifests in doing additional unpaid labor and hesitancy being away from their clients. Other literature notes that direct care workers sometimes struggle with being away from their clients or worry about them "off duty." These findings are congruent with and expand upon the existing literature, noting that care workers in home care settings are often asked to do additional labor by clients and clients' family members (Abrams et al., 2019; Karlsson et al., 2019).

These close relationships were perceived as beneficial for the participants in this research yet create personal and professional blurring of boundaries, which aligns with the literature. These close relationships often are useful for the work itself, and also provide companionship, reciprocity, and benefit all parities (Brouillette et al., 2023; Piercy, 2000). However, researchers note that role ambiguity or role conflict can occur in home care settings, as care workers are sometimes constructed as family and sometimes not and are often asked by clients and their family members to perform extra work tasks (Abrams et al., 2019; Barnhart, Huff, and Cotte, 2014; Denton, Zeytinoğlu, & Davies, 2002; Karlsson et al., 2019). Here, it is evident that there are conflicting tensions and complex interactions regarding direct care workers' and clients' relationships.

Strengths and Limitations

The topic of blurring boundaries and the notion that paid direct care workers providing care and services in individual homes for non-family older adults occupy a unique space as family/non-family are unique topics that are understudied in the literature. Through this work, I sought to amplify the voices of direct care workers which is reflected in extensive participant excerpts throughout this chapter. The qualitative methods deployed in this research captured the nuance and complexity of participants' lived experiences. Future research should examine the notion of being between, of blurring boundaries for direct care workers using other methods. For example, a nationally representative quantitative dataset with direct care workers providing care and services to non-family older adults in individual homes could help us to understand the prevalence of this phenomenon, or whether certain variables (such as years of experience) have a relationship with blurring boundaries (do more years of experience correlate with an easier time navigating boundaries?). Other qualitative studies could specifically focus on this notion of blurred boundaries and perhaps dig deeper into navigating these boundaries.

Conclusion

I argue and expand upon the need to view personal and professional boundaries as more fluid especially within home care settings (Abrams et al., 2019; Karlsson et al., 2019; Mears & Watson, 2008). Specifically, home care/home health agencies and society as a whole should use a new and more nuanced lens to understand the complex relationships between direct care workers and clients and understand that the intrinsic motivations behind entering this workforce can make people susceptible to blurring boundaries. Additionally, there must be more support for direct care workers regarding boundary navigation, such as by utilizing mechanisms of peer-support, managerial support, and organizational support with new understandings of these nuances. One specific example could be an onboarding process with more training around these tensions of personal and professional and how this strict division may not be helpful in navigating and understanding care work boundaries. This work contributes to the small yet growing body of literature suggesting that direct care workers in home care setting experience complex challenges navigating personal and professional boundaries in their roles. Home care and home health agencies must understand how the deeply intrinsic motivations for participating in the direct care workforce shape experiences of work, namely opening opportunities for close family like relationships and also exploitation, so that they can better support direct care workers in navigating these tensions.

CHAPTER 5: COVID-19 AND WORK

I. Introduction

In this chapter, I explore direct care workers' experiences of work while caring for older adults in the U.S. during the COVID-19 pandemic. Drawing on in-depth interviews with direct care workers, findings suggest that direct care workers experienced fear and risk calculations both at work and at home. As direct care workers shifted between interactions with their clients, whom they often formed close relationships with, and their spouses, children, and other family members at home, they experienced fear regarding the spread of the virus. This research demonstrates that direct care workers experienced heightened fear, stress, and frustration during the COVID-19 pandemic and explores 5 main facets: 1) fear and panic during the onset of the pandemic 2) caught in between, caregivers worried for their families and their clients 3) using multiple "layers of precaution" such as masking, vaccinations, etc. to cope with stress and worry 4) frustration at the state and agencies and 5) recognition and acknowledgement that home care workers are integral to the health care team.

In March of 2020 the World Health Organization declared that COVID-19 had become a pandemic, which illuminated and exacerbated social inequalities in the U.S., especially for direct care workers providing care and services to older adults in individual home settings. The COVID-19 pandemic has heightened job insecurity, job risk, and further strained care workers' mental and physical health (United Nations, 2020). Direct care workers are disproportionately women of color whose labor is deeply undervalued in the U.S., demonstrated by low wages, minimal benefits (health insurance, vacation time, etc.) and the invisibility of emotional and social labor in such work (Almeida, Cohen, Stone, & Weller, 2021; Institute on Aging, 2020; Loe, 2011; National Center on Caregiving, 2015; PHI, 2018; Stacey, 2011).

The pandemic has illuminated the difficult and important work of direct care workers. With an aging United States population that requires more care, direct care workers are in high demand, especially considering that as home health care is one of the fastest growing healthcare sectors, expected to grow by 34% from 2019-2029 (US Bureau of Labor Statistics, 2019-2020). Given that 80% of older adults live in the community and not in long term care facilities, experiences of home care workers are important to explore as they are increasingly utilized as essential labor in long term care (Hudson, 2014; Loe, 2011). As the pandemic continues, direct care workers face additional challenges and consequences both physically and emotionally.

Furthermore, the experience of direct care workers during the COVID-19 pandemic resembles experiences of other frontline healthcare workers, yet also departs from their accounts. During this time the media was replete with discussions about health care workers including doctors and nurses. However, direct care workers were "essential but undervalued" as Molly Kinder wrote in their (2020) article, highlighting these workers' and other health care workers' stories, arguing for more recognition for these workers, and recommending policies to support them such as hazard pay, paid leave, and the production of PPE (Guerrero, Avgar, Phillips, & Sterling, 2020; Kinder, 2020). Similarly, in the recent book *Elder Care in Crisis: How the Social Safety Net Fails Families,* the author demonstrates how the COVID-19 pandemic impact family caregivers and direct care workers alike, creating challenging decisions and also opportunities for important changes to our long-term care system (Abel, 2022). I argue that the fear and risk of contagion between their clients and their own family members is similar between nurses in hospitals and direct care workers, yet direct care workers continue to face additional challenges.

However, despite facing similar challenges and their status as essential workers, direct care workers' experiences received scant attention and significantly lower pay (Espinoza, 2022).

Qualitative research with home care workers in New York demonstrated that direct care workers felt a lack of support during the pandemic (Sterling, Tseng, Poon, et al., 2020). Another study using qualitative methods in Iran found home care nurses felt a "social stigma" around their work which included "feeling ignored," while also noting a lack of support from the home care agencies (Ghezeljeh, Shahrestanaki, Majdabadi Kohne, and Fakhari, 2022). This paper concurs with and expands upon this literature, suggesting that direct care workers worried about and feared COVID-19 transmission to their families and clients, yet their work was relatively solitary and isolated without the level of peer support and interaction that workers in a hospital or nursing home setting experienced.

Drawing on in-depth interviews with direct care workers, findings suggest that they experienced fear and risk calculations both at work and at home. As direct care workers shifted between interactions with their clients, whom they often formed close relationships with, and their spouses, children, and other family members at home, they experienced fear regarding the spread of the virus. Furthermore, some participants discussed their frustration at their state or home care/health agency during this time. Lastly, many of the direct care workers I spoke with noted how they should be perceived as an integral part of the health care team especially as frontline workers throughout the COVID-19 pandemic. This research demonstrates that direct care workers experienced heightened fear, stress, and frustration during the COVID-19 pandemic and explores 5 main facets: 1) fear and panic during the onset of the pandemic 2) caught in between, caregivers worried for their families and their clients 3) using multiple "layers of precaution" such as masking, vaccinations, etc. to cope with stress and worry 4) frustration at the state (geographic area) and agencies and 5) recognition and acknowledgement that direct care workers are integral to the health care team.

II. Methods

Methodology

I used Charmaz's constructivist grounded theory (CGT) for this research (Charmaz, 2014). The main principles guiding constructivist grounded theory include a focus on processes rather than themes, reaching saturation, and concurrent data collection and analysis. In constructivist grounded theory, data collection and analysis are concurrent, meaning that both processes happen at the same time; data from interviews influences the interview guide and the overall research questions which allows space for change based on emerging data. This allows me to see emerging facets of theoretical concepts, as well as shift or re-work interview questions and use theoretical sampling throughout the process of collecting and analyzing data. Constructivist grounded theory is useful to understand direct care workers' nuanced experiences more deeply and offers space for flexibility and change regarding data collection and analysis.

Further, CGT emphasizes researcher reflexivity, transparency regarding biases, memoing, and positionality. It is important to utilize a method which allows for discussion of researcher positionality and acknowledgement of a construction of reality by both researcher and participant and their interaction. Throughout this research, I have written extensive memos crucial to constructivist grounded theory methodology (Charmaz, 2014). Memo-writing has filled the gap between coding and writing results, acting as a place for reflection and expansion upon codes. I have written memos after each interview and after each coding session. Memo-writing as a piece of the analytic process has provided space for further reflection and theorizing and allowed me to stay close to the data.

Recruitment & Data Collection

I want to specify and operationalize my use of the term "direct care worker" throughout this paper. According to the US Bureau of Labor Statistics, there are three occupational categories comprising the direct care workforce 1) home health aides 2) personal care aides and 3) nursing assistants (sometimes referred to as CNAs) (Hunt, Yeh, & Fix, 2023; US Bureau of Labor Statistics, 2020). I specified this work to people who consider themselves home care workers, which included all three categories. For the purposes of this paper, I consider direct care workers people working to help others (including older adults or people with disabilities) with activities of daily living and/or household tasks and/or instrumental activities of daily living (see Chidambaram and Burns, 2022 for some specific examples) and/or some forms of medical services; typically work in individual homes; and are paid for their labor. More specifically, this work only focuses on (paid) direct care workers who primarily provide care and services for non-family older adults (but can also hold other positions, such as care work in various settings like nursing homes, hospice facilities, skilled nursing facilities, or work in another other occupation in general, etc.). Participants identified with a variety of terms, including home care workers, home health workers, personal care aides, CNAs, and companionship services workers. Participants held a variety of certifications, such as Certified Nursing Assistant (CNA) or Registered Nurse (RN). In order to use one term throughout this paper for consistency that is more encompassing of these categories, I have decided to use the term direct care workers.

I recruited participants through 1) convenience sampling and 2) snowball sampling by contacting home care or home health agencies via phone or email to distribute a flyer about this research. Additionally, I created posts on social media platforms including Facebook and Reddit for recruitment purposes. I conducted semi-structured interviews on the phone with direct care workers after screening for eligibility. Inclusion criteria included: adults aged 18 or older, live in the United States, work with older adults, work as direct care workers providing care and services in individual homes and are paid for their labor (but can also hold other positions, such as in a nursing home or other occupation in general), primarily provided care and services to non-family members, and were comfortable speaking in English. To protect participants' confidentiality, pseudonyms were used throughout this work. As illustrated in Figure 1, a participant flow chart, I reached 1,189 home care or home health agencies either by phone or email. 557 agreed to a secondary form of contact, either through email or by phone. Overall, 55 people were interested in participating in this research, 2 of which were ineligible according to exclusion criteria (they primarily provided care for children, not older adults), 10 did not complete an interview, and 45 completed an interview. Additionally, 2 interviews were excluded due to potential repeat interviews. Therefore, the final analytic sample was 43 interviews.

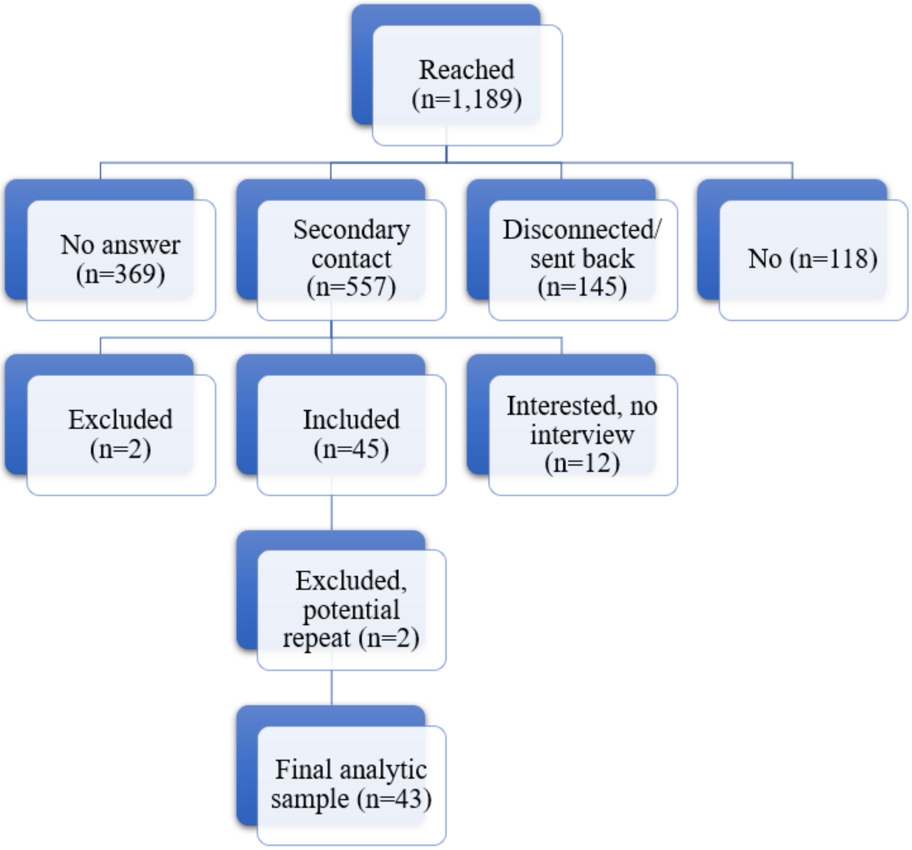


Figure 5.1. Participant flow. This flow chart shows that I reached 1,189 home health or home care agencies, and ended with a final analytic sample of 43 participants.

These interviews lasted between 20 and an hour and participants were compensated for their time. Interviews consisted of open-ended questions about topics such as a typical day at work, caseload and work scheduling, sources of support, self-care techniques, experiences during the COVID-19 pandemic, experiences with managers or supervisors, and why they chose direct care work as an occupation.

As this is a qualitative study, participants were asked about what identities were important to them and discussed in a conversational way. Some of these identities are reflected in the demographic Table 1 below, which includes participants' pseudonyms, gender identity, racial identity, number of years spent caregiving, and number of clients. This table only reflects information for participants whose excerpts appear in this paper. Consistent with the literature, the majority of the participants in this research identified as women of color. For this particular group (n=15), participants were either newer to the field with approximately 0-4 years caregiving or spent many years of their career in this occupation with 10 years or more in the field. Most of these participants had between 1 and 3 clients per week.

Table 5.2. Demographic table for chapter five. Demographics (n=15) for participants whose excerpts are highlighted in this paper.

	Gender Identity	Racial Identity	Years Caregiving	Number of Clients
Abigail	Female	Black or African American	10+ years	4 clients per week
Veronica	Female	Preferred not to say	Preferred not to say	1-2 clients per week
Pauline	Female	White or Caucasian	30 years	3-4 clients per week
Luna	Female	White or Caucasian	10+ years	2-3 clients per week
Daisy	Female	Black or African American	Less than 1 year	3 clients per week
Allison	Female	Black or African American	0-3 years	1 client per week
Olivia	Female	Black or African American	17 years	2-3 clients per week
Aubree	Female	Black or African American	Preferred not to say	3-4 clients per week
Brianna	Female	Preferred not to say	5+ years	1-3 clients per week
Cami	Female	Black or African American	20 years	Preferred not to say
Jenny	Female	Preferred not to say	0-3 years	1-2 clients per week
Evelynn	Female	White or Caucasian	11 years	1-3 clients per week
Finn	Male	Black or African American	18 years	1 client per week
Anthony	Male	Black or African American	4 years	3-4 clients per week
Jessica	Female	Honduran	8 years	1 client per week

Data Analysis

In the analysis of this research, the coding process occurred in two steps 1) initial coding and 2) focused coding. Initial coding is the first phase of coding. In initial coding, I focused on coding actions rather than themes, using more words and phrases with gerunds and using "-ing"; using active words allows me to stay more grounded in the data. Additionally, I have engaged in line-by-line coding in the initial phase of coding, which was mostly using hand-coding. With hand-coding, I aimed to color code transcriptions and code line-by-line, staying close to and engaged with the data. Initial coding occurred at the same time as conducting interviews and informed sampling, shifting interview questions if necessary, etc. In this initial coding phase, I constructed an extensive codebook before refining codes in the second phase of coding.

I refined my initial codes and started analysis across multiple interviews using focused coding, the second phase of data analysis. Part of focused coding also requires attention to words/phrases that have greater significance or occur more frequently across interviews. Additionally, I used NVivo coding software to help manage transcriptions, allow for cross-transcription analyses, and to refine the codebook.

III. Findings

These findings discuss a main theme of fear and risk during the pandemic, and the ways in which direct care workers navigate their dule role as "family members" and as workers in their clients' homes as well as perceptions about caregivers during this time. This research explores multiple facets of this topic, including 1) fear and panic during the onset of the pandemic 2) caught in between, caregivers worried for their families and their clients 3) using multiple "layers of precaution" such as masking, vaccinations, etc. to cope with stress and worry 4) frustration at the state or agencies and 5) recognition and acknowledgement that direct care workers are integral to the health care team.

Direct care workers' fear in the beginning of the COVID-19 pandemic

I asked direct care workers about their experiences during the COVID-19 pandemic. When discussing their experiences, the majority of participants expressed fear and worry especially during the onset of the COVID-19 pandemic. Many participants also discussed their confusion with new information daily and changing processes and protocols at work for example. One participant, Veronica, explained that working in direct care was "a lot of chaos" during the onset of the pandemic. When asked about concerns related to the COVID-19 pandemic, another participant explained her fear:

> *I was afraid especially watching the TV. I would try to not watch the news that much. When they started reporting and the numbers kept going up and up and up that's when it became reality. That's when it became scary. Like oh my God, what's gonna happen to us? It did put some panic in me. It made me realize how I could be one of those numbers. We didn't know what we were up against, we didn't know how it was spread, we didn't know what was out there. And it was frightening, we were really scared. – Pauline*

Pauline's experience reflects the fear, confusion, and worry that many of us experienced during the onset of the COVID-19 pandemic. However, Pauline and the direct care workers I spoke with also faced unique challenges because of their occupation, including a lack of environmental control at work, little support or supervision from their agencies, and worry for both clients and family members alike.

Caregivers caught in between – worry for clients and family

The notions of fear and risk calculation were intimately tied together when navigating direct care work in the midst of the COVID-19 pandemic. Participants were scared for their clients and their families as they were caught in the middle of both groups. They could expose or be exposed by clients on the one hand, and they could also expose or be exposed by their families and bring the virus to those they were providing care for on the other hand. When asked if she was working during the pandemic, Veronica had mentioned she felt scared, and when asked to explain she stated:

> *I was scared for my family actually during the COVID. That if something happened to me it's gonna go to my family as well because I am coming back home and it's difficult. I have to protect myself and then I took special precautions just to not have anything during the COVID…So all of these things happened during the COVID and it was a difficult situation for me to manage. – Veronica*

Building on this notion of risk and fear while at work and at home, many participants had family members with pre-existing health conditions or young children that had increased risks for contracting COVID-19. One participant, Allison, discussed dealing with the worry of needing to figure out how to move between these vulnerable populations, specifically her sisters with various health conditions and her client. This participant discussed the concept of "double worries," concerned for both her family and her clients:

> *COVID was horrible, working through COVID was horrible…I take care of my sister who is on oxygen and my other sister is on disability, and they live with me. During COVID it was really rough because you know just like the older people they're at risk to get it too, so I had double worries. – Allison*

Allison's description of her "double worries" for both family members and clients is similar to other participants' experiences during the COVID-19 pandemic. For example, when asked if he was worried during the pandemic, Anthony discussed worry for his family and his patients:

> *I was worried for my family, I was trying not to bring anything home. I have kids as well so it was a big factor as well for me, you know not bringing it home to my kids. I was always precautious myself before walking into the home you know start with my gloves,*

> *my mask, my shield over my face to kind of precaution myself and for the families and the patient as well. – Anthony*

Because people form close, reciprocal relationships working as direct care workers and are also closely tied to their spouses, children and other family members, direct care workers expressed concerns about exposure and transmission of COVID-19 because of their actions/involvement. The excerpt from Anthony clearly highlights how he was worried for his family and his clients and their families alike and took precautions to protect both groups. Similarly, Olivia and Aubree discussed their experiences during the COVID-19 pandemic and stated:

> *I made sure that I practiced good safety standards myself. I volunteered myself and went and got the shots because it wouldn't have been fair for me to go around and expose my clients and get them sick and because you know then people could die. And so I knew that they were at risk, because of their health status, so it was important for me to stay healthy and practice good CDC standards. – Olivia*
>
> *That was very very very stressful. You have to make sure that you are careful for yourself and your client. That was hard because you can't tell people who they can and can't have in their homes. You can clean and sanitize when you are there but when you're not there you don't know what you're walking into when you walk back in…You don't want to get something and you didn't want to pass it on to your clients. – Aubree*

These excerpts continue to highlight that direct care workers emphasized caution for not only themselves, but for their clients as well. They discussed their role in protecting their clients by following CDC guidelines and sanitizing often among other actions. However, despite being "careful," using precautions, enacting sanitizing protocols and other safety measures, the majority of participants contracted COVID-19. Many participants discussed that it was difficult being away from work for several weeks, managing their symptoms, and navigating worry for their clients even while ill themselves. For example, one participant discussed how she was diagnosed with COVID-19 and continued making telehealth calls with her clients because she "had to know they were okay:"

> *I was still making telehealth calls when I was sick [with COVID-19]. I would prop myself up and I would make so many calls and I'd lay down for 15, 20 minutes try to rest my body. Then I'd get back up, make more calls. You know, I had to hear their voices. I had to know they were okay. I had to know that they had everything that they needed because to me it was like okay I can get through this but I need to be there for them. – Pauline*

In this excerpt, Pauline recalled that she continued to work virtually when she was ill with COVID-19. This clearly highlights that not only were participants afraid for their clients, but also experienced risks to their own health. This also illuminates the deep relationships direct care workers have with their clients. Participants discussed how they were caught in between their families and their clients during the COVID-19 pandemic, worrying for the health and safety of both groups and navigating movement between these vulnerable populations.

"Layers of Precaution"

Another facet of fear and risk was the ways in which participants used multiple methods of protection to relieve that fear or worry. Aubree's and Olivia's experiences detailed in the previous section discussed using various precautions and following protocols to protect themselves and others against the spread of COVID-19. Further, several participants discussed that they felt safer given the development of the COVID-19 vaccine and protective protocols such as masking in public spaces. When asked if she ever felt worried during the pandemic, Jenny explained:

> *I have not been worried because I have been current with all my vaccinations and wherever I go it's already kind of like my way of doing things. Like even if I'm in school nobody else is wearing masks I still do, and if I go to the grocery store I wear a mask. I feel like I am taking another layer of precaution besides getting vaccinated…I feel lucky I have not gotten COVID since I have never gotten it. So maybe that's why I feel more safe*

> *I guess you could say, that my ways of going about things have worked. I don't really worry about it too much but I do in a way worry about it because of the precautions that I take. – Jenny*

In this excerpt, it is evident that the use of "layers of precaution" including up-to-date vaccinations and wearing masks in public made Jenny feel "more safe." When asked what it was like during COVID-19, another participant Jessica noted "Oh it was, you know I was a little scared, but I take my precautions and all the things I have to do. But that's the only thing. I never, you know, missed one day. I was always working." Jenny and Jessica echo many direct care workers' experiences that vaccinations, disinfecting, social distancing, and masking among other methods of protection helped them to feel less worried regarding COVID-19 transmission. Abigail and Luna shared their experiences as well:

> *We had to change our clothes. When we come outside a client's house, we had to make sure that our clothes was in a bag tied up because it couldn't touch no person. So it was rough during the pandemic because everything and every time at work you had to change clothes because you don't want the clients sick. – Abigail*
>
> *I think my fear actually was more that I have a mother that I take care of who had a stroke and high blood pressure and so my biggest concern was not giving it to her. So I had this system where I would you know sanitize before I go into the home, go straight to the shower, my clothes went right into the washer, you know. I had a whole set up in the back of my car so if need be I could shower before I went into the home it was like a camping set up and a whole hand washing station. – Luna*

For both Abigail and Luna, changing clothes was an important part of ensuring that clients and family members remained healthy and preventing the spread of COVID-19. Many participants shared that various "layers of precaution" and protocols helped relieve some fear and worry regarding COVID-19 transmission for both clients and family members.

Frustration at state or agencies

Although only a few participants discussed frustration at their state or home care/health agency, this theme is important to explore to understand how some direct care workers felt during the COVID-19 pandemic. One participant, Brianna, explained her feelings of resentment at the state for "hiding" while she and other direct care workers were "risk[ing] [their] lives":

> *(Sigh) we were told by the state that we had to be out there regardless. And they're all locked safely in their homes. And that was a little bitter tasting. We refused to shut our office down if our caregivers had to be out there working in it. We certainly were not going to be hiding at home…I do still feel a little resentment for our state I have to say. Them hiding out and issuing us orders that you know you have to be in there regardless. And then it just seems like they're telling us go risk your lives regardless if somebody has COVID or not, you still have to go into the homes. The hospital got all these supplies and stuff, and we had to scramble to find supplies. It was difficult. And it's hard on small agencies to buy all that stuff when other places were getting them shipped to them and given to them. So yeah maybe there is a little bit of resentment still there. – Brianna*

Brianna also highlighted how it was difficult for small home care agencies to find and buy personal protective equipment (PPE) for employees whereas other larger agencies or hospitals were given supplies or had more funds and resources to procure PPE. Another direct care worker, Cami, expressed similar concerns about the home care agency "hiding" while she "showed up" for clients with COVID-19:

> *He [client] was discharged from the hospital and he was still COVID-19 positive. Nobody wanted to come in. I got put in a situation where his transfer ability declined and at least the agency should have assessed him before an aide was sent there, they just threw a person like me there, that wasn't right…He's got COVID, been in the hospital for 2-3 weeks, at least they should have sent another co-worker. You're telling me I still have to be there whether they have COVID or not but then you sitting on your ass and saying "I don't want to be there." But you trying to use the guideline for they are still patients and clients we should always care for them whether they have COVID or not but then you're hiding behind the laws. You send me out to go get COVID but then you protecting yourself trying to act like it's my job but it's your job too. I showed up. – Cami*

In this excerpt, Cami shared a situation in which she wanted support from her agency with a COVID-19 positive client, and yet felt that they were "hiding" and "protecting" themselves. Both Brianna and Cami expressed that they felt like people at the state level or agency level were "hiding" while they were putting themselves at risk as frontline and/or essential workers. They expressed anger and feelings of "resentment" being put in these situations. Their experiences are important to understand because some home care workers felt frustrated at the way they were treated during this time by the state or agencies.

Acknowledgement and Recognition

Many of the direct care workers I spoke with noted the lack of acknowledgement and recognition for their work. Several participants felt that they were not included as part of the care team. When asked what she would change about her job, Evelynn explained that she would change "the perception of caregivers":

> *I think the perception of caregivers. I think that typically caregivers are looked upon as a low pay scale, you don't need an education typically, you know that kind of position. Where I really feel like we provide an essential part of care for a person's life and it should come with, I think, a little more…I just don't see that there is a lot of importance placed on it and if anything I feel like the pay is better now post covid…but pre covid the pay was poor. So I would change the pay rate, the way we are looked at, the way society looks at us, and just benefits in general. – Evelynn*

As Evelynn suggested, direct care workers' lack of recognition can be seen in the lack of benefits, vacation time, sick leave, poor compensation, etc. that is well-documented in the literature. She noted that she would change "the way society looks at" direct care workers and highlighted that direct care workers "provide an essential part of care for a person's life." Other participants shared this sentiment as well. For example, Finn, who worked as a nurse prior to working in home care settings, discussed how caregivers "are lesser" than other health professions and not counted as part of the health care team:

> *If you look in the medical field, they don't even count us as being a part of that field. Caregivers aren't the same, they are lesser than any medical profession that is. I tell people like when I worked in nursing. A doctor would not be successful as he is without that nurse. And why is that? He don't know nothing about the damn patient until the nurse tell him. The nurse does all the work, all he did is went and looked in a book [laughs]…If I was to call the ambulance for [my client] right now, it's hard to go from zero – you don't know nothing about this person's medical history, you don't know nothing about this person – to help them, the patient is more as risk of dying if you don't know nothing about them. But the caregiver is the patient's chart. – Finn*

In this excerpt, Finn further noted how home care workers are integral to the care of older adults, stating that "the caregiver is the patient's chart." In addition, other participants noted that particularly during the COVID-19 pandemic, they felt less support or appreciation in U.S. society in general. When asked if there was anything else she wanted to share that I did not ask or mention, Pauline noted:

> *You know we hear a lot about the nurses and the firefighters and the police and everyone going in and you know showing up for their jobs every single day and you know dying left and right from COVID and everything. And I applaud them. But I think the other heroes here were lost in the shuffle, which is the girls and the guys that would go out and do the home care, and take care of the elderly and try to keep them going forward. – Pauline*

Pauline noted that direct care workers were "heroes…lost in the shuffle" who should be appreciated for their work as frontline care team members during the COVID-19 pandemic. Direct care workers' efforts as integral members of the care team should be appreciated and recognized for their work during the COVID-19 pandemic and beyond.

IV. Discussion and Conclusion

This research suggests that direct care workers experienced fear and often thought through risk calculations during the COVID-19 pandemic in ways that were both similar to and different from other frontline healthcare workers. Direct care workers moved between clients' environments and their families and were fearful and worried about being exposed to and/or exposing each group. Direct care workers often faced risks themselves getting COVID-19 and utilized "layers of precaution" to help cope with and relieve stress and worry. Some direct care workers also expressed frustration at the state or agencies for "hiding" while they were working on the front lines during the COVID-19 pandemic. Direct care workers expressed that they felt underappreciated and not seen as members of the care team.

This research has implications for providing better support to direct care workers based on new understandings of their experiences throughout the COVID-19 pandemic. Home care and home health agencies must do more to support direct care workers' mental and physical health such as training on infection control, offering mental health benefits under insurance policies, implementing paid sick leave, and providing resources to home care workers seeking help among other things. This work demonstrates the need for more appreciation for direct care workers and their role as a critical part of the healthcare system. Importantly, this work has implications for bolstering the economic and social safety net for direct care workers in the US.

CHAPTER 6: INSTITUTIONAL DISENFRANCHISED GRIEF

I. Introduction

Despite the known consequences of grief and lack of administrative support, little qualitative research with direct care workers providing care and services in individual homes specifically details processes of grief and loss. In 43 interviews (n=43) with direct care workers, I explore the landscape of how direct care workers navigate experiences of their clients' deaths and the mechanisms of social and structural support. I argue that direct care workers are vulnerable to and experience disenfranchised grief due to 1) the social construction of their relationship with clients that does not see the grief as legitimate and 2) further erasure and/or delegitimization of their experiences by a lack of home health or home care agency/institutional support. This work has important implications for policy implementation and practices to better support direct care workers navigating grief when their clients die. Some examples for financial and social support include paid bereavement leave, mental health coverage under insurance, and the implementation of peer-support groups.

There are over 4.8 million direct care workers who provide care and services to older adults in the U.S. (PHI, 2023). The older adult population is growing, as is the demand for home and community-based services as more older adults seek to age in place or age at home. This workforce is disproportionately comprised of women of color and faces challenges such as low pay rates and minimal benefits (Almeida, Cohen, Stone, & Weller, 2021; Institute on Aging, 2020; Loe, 2011; National Center on Caregiving, 2015; PHI, 2018; Stacey, 2011). Despite their critical role in our long-term care system, direct care workers (CNAs, HHAs, and HCAs) providing care and services in individual homes receive little support or resources regarding experiences of client death and navigating grief.

Some grief is considered disenfranchised grief, which “refers to a loss that cannot be openly acknowledged, socially sanctioned or publicly mourned” (Doka, 2005:87). Some common examples of disenfranchised grief include grief regarding an ex-spouse, loss of a loved one due to “stigmatized death” such as suicide, or the loss of a pet (PsychCentral, 2021). Other definitions in the field of nursing, for example, state that “disenfranchised grief is experienced during bereavement loss and after the loss of something personal, physical, or psychological in which a person lacks societal witnessing, empathy, or validation of their loss” (Weiss, Florell, Oman, & Sousa, 2023:92). Direct care workers have been shown to experience disenfranchised grief wherein their grief over the loss of their clients is not often acknowledged or supported in society or in their agencies/places of employment. Some literature suggests that the emphasis of task-oriented work such as making beds, toileting, showering, clothing, feeding, also known as “bed and body work,” can often be prioritized over processing grief that can lead to disenfranchised grief and more complex grieving processes (Anderson & Gaugler, 2007; Gubrium, 1975). Neoliberal ideals in the long-term care system, such as making profits, often disincentivize spending time with clients and prioritize tasks which may discourage direct care workers from processing grief.

Research demonstrates that direct care workers may face consequences of grief similar to family caregivers and that closeness of client relationships may deepen grief processes as they often develop “family like” ties (Boerner et al., 2015:215). This grief can also contribute to burnout and mental health issues, which are often overlooked (Boerner, Gleason, & Jopp, 2017:317). Other literature points to the cumulative nature of grief, such that experiences of client death add up over time (Marcella and Kelley, 2015). Additionally, research notes that preparedness for client death and closeness of client/caregiver impacted the grieving process, such that grief intensified the closer/deeper the relationship (Boerner, Burack, Jopp, & Mock, 2015; Anderson & Gaugler, 2007). Lastly, research notes that direct care workers' experiences of grief symptoms were similar to that of family caregivers and disenfranchised grief can contribute to higher levels of stress and burnout (Boerner, Burack, Jopp, & Mock, 2015; Testoni et al., 2023).

Direct care workers are underpaid, undervalued workers in the U.S. both currently and historically and may experience layered losses when their clients die which can further complicate the grief process (Berry and Bell, 2012). For this workforce, the loss of client is not only loss of a person close to them but also a loss of finances, and they often need to find a new client or is assigned a new client quickly. Research notes that direct care workers experience care transitions when the death of a client occurs; in these transitions, workers not only lose a person and a relationship, but also essentially loss of income especially as direct care workers providing care and services in individual homes typically have a smaller number of clients on average compared to workers in other settings such as nursing homes (Riesenbeck, Boerner, Barooah & Burack, 2015; Wladkowski, Kusmaul, & Latimer, 2021). This layering of loss may compound grief processes for direct care workers.

Administrative systems lack 'formal' processes and opportunities for care workers to navigate grief and death of their clients. Research in adjacent cases (long term care homes) specifically notes that death is hidden in long term care systems and rarely discussed, and there is a lack of support at the organizational level (Marcella and Kelley, 2015). One qualitative study with administrators and supervisors from continuing care retirement community (CCRC) facilities found that "only 3 of the 10 administrators discussed the importance of extending [bereavement] services to the staff" and noted a lack of "formal" support systems offered through employers (Chahal, Ewen, Anderson, & Miles, 2015). In another study with administrators of several home care agencies, researchers found that there was a lack of paid time off, little emotional support, and a lack of training on end-of-life care (Tsui, Franzosa, Reckrey, LaMonica, Cimarolli & Boerner, 2021). Additionally, research suggests that direct care workers would like more support. In a quantitative study which includes both "home care and institutional settings," participants "said they would use additional [bereavement] support services if they were offered" (Rickerson, Somers, Allen, Lewis, Strumpf & Casarett, 2005). Home health aides in hospice settings "…also expressed a desire for more support, both formally from the hospice and informally through social connection" (Ghesquiere & Bagaajav, 2020: 622).

Despite the known consequences of grief and lack of administrative support, little qualitative research with direct care workers specifically details processes of grief and loss. The purpose of this paper is to qualitatively explore the landscape of how direct care workers navigate experiences of their clients' deaths, whether and how they create space to grieve, and understanding the mechanisms of social and structural support available to them. First, I discuss how participants formed close, family-like bonds with their clients and how these losses are like the loss of a family member. Then I note how direct care workers are vulnerable to disenfranchised grief given the lack of agency/institutional support and little social support systems, which is illustrated in the fact that many participants quit/switched jobs or contemplated doing so in the wake of a client's death. This work has implications for policy implementation and practices to better support direct care workers navigating grief when their clients die. Some examples for financial and social support include paid bereavement leave, peer-support groups, and mental health coverage under insurance.

II. Methods

This chapter uses in-depth interviews (n=43) with direct care workers providing care and services to older adult non-family members in individual homes guided by constructivist grounded theory (Charmaz, 2014). More specific information about this study population, recruitment processes, data collection procedures, and data analysis can be found in the methods chapter of this dissertation (chapter 2).

Table 1 below depicts demographic information only for participants whose excerpts appear in this chapter. Reflective of the overall sample, the majority of participants in this smaller sample identified as women of color. This group was split regarding years of experience caregiving, with a large portion of participants with 0-5 years of experience and another large portion of participants with over 10 years of experience. On average, this group had two clients per week.

Table 6.1. Demographic data chapter six. Demographic information for participants whose excerpts appear in this manuscript (n=15, overall sample n=43).

	Gender Identity	Racial Identity	Years Caregiving	Number of Clients
Pauline	Female	White or Caucasian	30 years	3-4 clients per week
Allison	Female	Black or African American	0-3 years	1 client per week
Olivia	Female	Black or African American	17 years	2-3 clients per week
Brianna	Female	Preferred not to say	5+ years	1-3 clients per week
Cami	Female	Black or African American	20 years	Preferred not to say
Jenny	Female	Preferred not to say	0-3 years	1-2 clients per week
Evelynn	Female	White or Caucasian	11 years	1-3 clients per week
Jonathan	Male	Black or African American	At least 3 years	1 client per week
Willow	Female	Black or African American	3 and a half years	3-4 clients per week
Isabel	Female	Preferred not to say	10+ years	2 clients per week
Robin	Female	Jamaican	2 years	2-3 clients per week
Natalie	Female	White or Caucasian	15 years	1 client per week
Bailey	Female	Preferred not to say	11 years	1-2 clients per week
Thomas	Male	White or Caucasian	7+ years	1 client per week
Kathleen	Female	White or Caucasian	20 years	3-4 clients per week

III. Findings

Family-like relationships and family-like loss

Direct care workers form close bonds with their clients. They discussed feeling like family, despite primarily providing care and services to non-family older adults. Jonathan discussed his close relationship with his client and stated "he's like my dad [laughs]. I call him pops and he calls me son, we are really close." In a similar way, Willow discussed a family-like bond with her client:

> *She [client] made me welcome like I am home. I interact with her and her family, it's more like "okay come in, you're family, you're no aide you're family." So it's the warmth and the love that I get from my clients and their family, it's awesome. – Willow*

Willow described how she felt like a member of her client's family more than she felt like a direct care worker, echoing Jonathan's experiences as well. Here, we see that direct care workers form close relationships with their clients, in opposition to commonly held beliefs about direct care workers and their clients which suggest that this position is 'just a job.' Willow, Jonathan, and other direct care workers explained that they felt like family with their clients.

Another aspect of this work is exploring interactions with direct care workers and their employers at home health/home care agencies. Like Willow and Jonathan, Isabel also noted establishing family-like bonds with clients. However, Isabel explained how the home health/home care agencies often discourage such close relationships:

> *I've always been very very close…You need to treat them like it's your family. They [agencies] might say don't get close to your clients but that doesn't make any sense. You're taking care of somebody, how are you not supposed to get close? [The agencies say] "don't get close to your clients because if they die you're gonna…", everybody dies. But you should really consider them as family because then you are going to treat them in a different way and they should be treated like humans, not like a job. – Isabel*

Isabel's experiences highlight the family-like bonds established between direct care workers and their clients, and further explains how institutions (home health/home care agencies) discourage this closeness because of difficulties navigating loss when clients die. Rather than institutions offering support mechanisms for encountering grief to their employers, they often discourage those close relationships with clients instead. This picture is further illuminated in

Brianna's experience, which highlights that although close, family-like bonds are formed, direct care workers are not family members. She stated:

> *I make a commitment to them that I will see them out of this world. And it's extremely close. They become family. They come to our house for holiday dinners, not so much with COVID-19, that put a squelch on that. But they come to our house for Easter and Thanksgiving and Christmas. And my family makes a commitment to cook the food and serve them and give them rides back home or a caregiver brings them. We become very close…you have to remember that even though we've been with these people for a long time they're not our loved ones, it's not our mom it's not our dad it's not our brother it's not our sister. We've taken care of them yes and we love them, and we have a harder time with some than others, you know, depending on how long we've been with them but there is a difference. – Brianna*

Brianna explains how she and her family form close relationships with her clients, such as partaking in holiday celebrations and family dinners. Later, however, Brianna noted that "there is a difference" between clients and family members. It is unclear here whether this is an example of internalization of the rhetoric from institutions discouraging close relationships and separating the categories of family and clients when many direct care workers genuinely feel like family with their clients. It is evident that Brianna, despite forming close bonds with her clients, distances herself from this notion of family.

In previous excerpts, we have seen that direct care workers form close bonds with their clients, often feeling like family despite providing care and services to non-family members. Robin discussed the events surrounding her client's death which demonstrates how the close emotional bond makes her susceptible to grief. She explained:

> *She [client] was the one who encouraged me for everything. She would look at me and say "Robin, you need to go and finish your high school diploma." Because she was a former maths teacher. And that lady would make sure, when I come to her she the first thing she said before she said good morning was "did you do your homework? Did you do your school things?" (Laughs.) And I would say "yes." And she said "okay good, I want to make sure you get that before I leave this Earth." And when I got it, she was like a bright star in the sky, she was so happy for me, and I told her you helped me do that…That's how we are like a team, two peas in a pod…And I was on my way going to*

> *work was just about to drop off my daughter to school. And my company called me and said "uhm we have some bad news" and they said "she died this morning." I said "what." And they said "where are you now?" And I said "I'm on my way to go to her." And I said "I'm still gonna go and see her, I want to see her." And I went and I saw the daughter and I asked her permission and she said yes so I went in. And she was lying down in the bed. And I went over to touch her, and I said "goodbye girl, goodbye my friend. We had a wonderful time. And I am not vex with you, and I am not sad if you leave me right now" but, I knew. I knew it was time so…"I hope you have a peaceful life in heaven. You deserve it. You are one warm-hearted woman." And I touched her forehead, and I walked outside the room… When she died…Oh my God…It hurt my heart so much. But why? I know she was suffering so there was nothing I could have done. She was more than a companion, I more than a caregiver. – Robin*

Here, Robin discussed her close reciprocal relationship with her client and illustrates perhaps a mentorship or even parental relationship in some ways. Furthermore, this counters the stigmatization that often accompanies carework that older adults only receive care and highlights how Robin's client contributed to achieving her goals, supported her in her educational journey, and provided a valuable relationship to Robin, who had experienced hardships as she immigrated to the U.S. and searched for a meaningful occupation. Robin recalled her client's death, saying goodbye, and how that experience "hurt [her] heart" and again emphasized how she felt like more than a direct care worker. This is a typical example of direct care workers' reciprocal relationships with their clients, mirroring Jonathan and Willow's accounts from earlier, and indicative of the grief and loss that a client's death can elicit.

The majority of direct care workers noted that the death of their client was the most difficult aspect of their work. Most direct care workers I spoke with discussed their family-like relationship with clients, and how this heightened the difficulty of when their clients passed away. For example, Oliva stated:

> *I've had a few that transitioned, they end up on hospice care and I had become so close to, I've always been close, it's like taking care of family members to me and when they die that's been hard for me. That's the hardest part of my job. You know I miss them. – Olivia*

Here, Olivia noted how in her work, she felt like she was "taking care of family members" and expressed that the deaths of her clients were difficult, akin to losing a family member. Evelynn expressed similar feelings regarding the formation of family-like relationships with her clients and further explained the difficulties of watching her clients declining in health over time:

> *The negative part of this career is when folks start to really decline and you're losing them but they are still with you if that makes sense…It's difficult. It is like a family member really, I get choked up when I think about it [cries]. This one elderly gal that I took care of most recently, I only worked with her for about six months but she was just a real sweetheart and it was so fun to spend time with her and make an impact on her day. Very difficult, very similar to a family member when you work that close with them you can't help but you know form a bond. – Evelynn*

When asked if there were any negative aspects of this work, Evelynn recalled the difficulty watching clients decline in health and eventually die. This hints at anticipatory grief, which is common among direct care workers, which occurs when people begin experiencing grief or distress before a person dies. She discussed her family-like relationship with a specific client and said she "can't help but" to have a close relationship. Here, this may imply that she 'shouldn't' form a close bond, perhaps harkening back to an internalization of institutional or societal discourse about not having close relationships with clients.

Both Olivia and Evelynn highlighted how they felt a family-like relationship with their clients who had passed away and described that experiencing that loss is difficult part of working as a direct care worker. A few direct care workers I spoke with even noted how the death of their client, or the possibility of their death was "scary" at times. Although this was less frequent among these participants, these experiences and feelings are important to highlight. In discussing her experiences, Bailey explained:

> *I've had 4 of my clients pass and that's really hard to know that that's going to happen and that could happen and being responsible for that much at a time sometimes. It's not*

> *something you want to do when you know that it's coming close and it gets scary sometimes like I am not a medical professional as far as I haven't been trained and I don't have a license and so there's a lot of things I'm not allowed to do… – Bailey*

Bailey shared her feelings about the challenges she faced when clients die, particularly regarding fear caused by high levels of responsibility along with a lack of training around death, dying, and end-of-life care. Additionally, for many direct care workers, there are restrictions on actions they can and cannot perform, such as administering IVs or medication, which for Bailey resulted in heightened fear. Participants shared their experiences of client death, noting their often close relationships and feelings of sadness and fear that made them more vulnerable to experiences of grief.

Disenfranchised grief

Direct care workers are vulnerable to and experience disenfranchised grief due to 1) the social construction of their relationship with clients that does not see the grief as legitimate, that they are not close enough, etc. and 2) further erasure and/or delegitimization of their experiences by a lack of agency/institutional support. Direct care workers face both a lack of social or interpersonal support and a lack of agency/institutional support. This is further emphasized and demonstrated by many caregivers switching jobs or contemplating career changes due to grief and loss.

Lack of Social Support

Despite close, family-like bonds with clients, direct care workers often did not receive social support similar to family members when experiencing the death of their client. Jenny discussed her experiences when her client died and stated:

> *But I just think it was a little harder because it was like during the holidays. I was sad that she [client] didn't get to spend it with her family and such. But it I got distracted also within the holidays, my family was there for me even though they didn't really know what*

> *was going on. I don't recall doing anything like with the intention of just feeling better it just kind of happened. And like was having people there for me but not necessarily with them knowing. – Jenny*

In this excerpt, Jenny noted how her family "didn't really know" what was happening, that she was struggling with the loss of her client. When a family member passes away, the death is usually known, discussed, and processed together among family members or even as a whole community. However, despite feeling family-like bonds and a family-like loss, Jenny's family was not able to identify with her struggle in navigating grief. In a similar way, Thomas discussed the importance of remembrance and talking to others about positive memories with clients who have passed away even when others do not know the client or situation. Thomas explained:

> *I always just try to remember that person, like if something reminds me of them it always feels good to bring up whatever reminded me of them even if the people I'm talking to don't even have a clue. I just try my best to remember people. – Thomas*

Thomas explained that he tried to "remember people" after their death, even if folks "don't even have a clue" about the person who died or the situation surrounding his grief. Thomas also echoes Jenny's feelings discussed earlier about the importance of support from people, yet they are often unaware of the client's death. Experiences of grief for Cami led to more isolation and processing alone. She stated:

> *I had a client of mine and he happened to pass away from COVID, so that really sucked, it really did… So that really frightened me, shook me up…It really did bother me mentally and yeah it affected me a lot I kinda didn't work as much hours and it also affected me physically too…not going outside or [I] didn't want to be around too many people. So it mentally and physically affected me too. – Cami*

The experience of her client's death impacted Cami mentally and physically, and directly lead to isolation from work and other people. Cami's experience highlights how for some direct care workers, the death of their client(s) can lead to further isolation. Although direct care workers often have family-like bonds with their clients, they do not receive institutional or personal support in the same manner that family members would receive.

Lack of Institutional Support

Institutional/agency support varied greatly from participants reporting that counseling services were offered, unsure if services were offered, or noting that services were not offered at all. Though there was a range of institutional support, the majority of participants who experienced the death(s) of their client(s) were unsure or unaware of any institutional support mechanisms such as counseling or peer-support groups. When asked whether the agency offered support, Kathleen shared:

> *I'm not sure about [agency]. I usually go to the viewing [at other companies] and then see because sometimes the family just wants them [private] depending on the situation. – Kathleen*

It is evident that Kathleen was unsure about support or resources offered at her current agency. She explained how she often attended a viewing or a wake after her client(s) pass away at other companies, which occurs when friends, family, and community gather to honor the deceased person typically before a funeral. However, Kathleen was unsure about resources and options for navigating grief and loss at her current company. Similarly, Cami was unsure of resources or support offered at her agency. Cami switched from working in a nursing home setting to a home care agency. When asked about resources that the home care agency offered after the death of her client, Cami stated:

> *No, I never seeked that so I didn't know if they had that. The nursing home closed down so who can I call for help? – Cami*

This excerpt not only shows that Cami was unaware of any resources for support but also begs the question, what happens when nursing home or home care agency closes? Cami felt she had no one to "call for help." However, some participants shared that their agency offered resources for support regarding client death, though it was less frequent in among this participant population. Brianna discussed agency support and stated:

> *Grief counseling…Yes I have, there's grief counseling offered through our hospice system. – Brianna*

Here it is important to note that grief counseling, although offered, was only available through the hospice system. Offering grief counseling in a separate branch of the home care agency could create barriers to accessing this support, as in Brianna's experience, it was not offered through her regular work environment. Additionally, there were a few instances of participants explaining that they were not offered support. After sharing about the death of her client, I asked Allison whether anyone at the agency offered her support or resources and she said "not really." This section highlights that some participants faced challenges coping and navigating their experiences of grief with varied support from their agencies, however the majority of participants were unsure of institutional support or resources offered.

Switching Jobs or Contemplating Quitting

Direct care workers often reported that they switched professions or contemplated quitting their job providing care and services for non-family older adults in the U.S. often due to difficulties navigating death and loss. For example, Thomas, who we heard from earlier, stated that he had switched careers due to the "emotional toll" of the death of his client yet went back to direct care work later. He explained:

> *I took care of a guy named [redacted for anonymity] and him and I got really close so I managed his private in home care. I was at his house taking care of him and hanging out with him 4 or 5 days a week for like 6 months so we became really close…It just always*

> *takes an emotional toll. That's why I tried T-Mobile out because it just, it gets sad sometimes you know. – Thomas*

Thomas explained that he formed a close relationship with his client and switched in and out of direct care work due to the difficulties of loss. In a similar way, Natalie shared her experience when asked "how do you process" the losses:

> *You try to figure it out in your head but you can't because it makes you crazy. You just have to move forward I mean it's tough and it's sad but then it's a part of life. I mean it's a scary part but it's a part of life unfortunately you know. I mean I contemplated quitting and finding another job but you know it's gonna be the same no matter where you go because it's just there. – Natalie*

Here, Natalie noted how it is "tough" and "sad" and "scary" to deal with the death(s) of her client(s). She stated that she had thought about switching careers due to these difficult experiences. In a similar manner, Pauline explained how she shifted in and out of direct care work because of burnout related to losses. When asked "what advice would you give to someone newly entering this field," Pauline stated:

> *I'll be the first one to tell a newbie coming in that this can be a burnout job. It can be. Mainly because of loss. The end result is we're going to lose them. But we are fortunate to be in their lives when we are because this is when they need us most. And there's been times throughout my career, I've been working for over 30 years now that I have stepped out of the healthcare field and I have gone into something totally opposite just because of the burnout. But then I find myself being pulled back in again. – Pauline*

Here, Pauline discussed her feelings of knowing that clients would eventually die, experiencing burnout, and how this led to moving in and out of the direct care workforce. Some participants sought career changes due to the difficulties of working as direct care workers and struggling with the deaths of their clients.

IV. Discussion

This research suggests that direct care workers experience disenfranchised grief at both a social and institutional level at their home care/home health agency wherein their grief from the deaths of their clients are not constructed or considered as legitimate, and face further delegitimization of their experiences by a lack of agency/institutional support. Disenfranchised grief as a framework is most commonly used in relation to social, more micro level interactions. This work expands upon the disenfranchised grief framework by suggesting that this can occur at an institutional level as well for direct care workers, especially when they are not supported by their agencies.

Throughout this chapter, I demonstrate that direct care workers close, family like bonds with their clients and often experience a family-like loss when their clients die. However, direct care workers do not receive the same support at a social level as family members when encountering death, loss, and grief. Furthermore, the majority of direct care workers were unsure of any available institutional support mechanisms to help navigate their grief after their clients died.

This research has implications for organizational change, and I argue that home care and home health agencies should increase support for direct care workers around grief and loss, as they will likely experience the death(s) of their client(s) as part of this work. For example, offering peer-support groups, training programs specifically on death, end-of-life care, and bereavement, or grief counseling services could be helpful strategies for direct care workers encountering grief. This research also has structural implications for bolstering the economic and social safety net for home care workers, such as policies for health insurance and mental health coverage, paid time off for bereavement (or bereavement leave), and other social support mechanisms.

CHAPTER 7: CONCLUSION

I. Introduction

Because of personal experiences growing up and watching my grandparents provide care and need home care and services themselves, I was interested in exploring direct care workers' experiences while providing care and services in individual homes. Although these personal experiences drew me to this dissertation topic, this work is important as this workforce is a critical part of our long-term care system and is an understudied population. Additionally, older adults and care workers were disproportionately impacted by the COVID-19 pandemic which continued to influence important questions around aging, carework, and health equity.

Throughout this dissertation process, I have found that discussions about the direct care workforce are often deficit oriented, listing the risks and consequences to providing care and services to older adults (even for other populations, such as family caregivers). There are some exceptions which discuss the formation of fictive kin relationships. I noticed that studies often spotlight positive or negative experiences, rather than discussing complicated experiences and processes. This dissertation work extends beyond these opposing narratives and highlights the complexity and nuance of care work in homes for direct care workers; instead of focusing on only positive or negative experiences, this work features the interconnected processes inherent in this work.

All qualitative chapters feature this notion that intrinsic motivations for joining this workforce open opportunities for positive reciprocal relationships and meaning-making, and yet also create opportunities for exploitation and a lack of support at micro and macro levels. This tension builds and manifests in blurring personal and professional boundaries for direct care workers evident in a variety of experiences throughout the COVID-19 pandemic, such as performing additional labor and grief.

In the first section of this chapter, I present a summary of the findings from each chapter of the overall dissertation, including 1) chapter three, the quantitative content analysis on emotional labor and pay rates for home health aides 2) chapter four, which highlights how direct care workers experience blurring personal and professional boundaries that often result in performing additional unpaid labor 3) chapter five, the discussion on direct care workers' experiences during the COVID-19 pandemic and lastly 4) chapter six, wherein I argue that direct care workers experience disenfranchised grief when their grief experiences are not legitimized socially or institutionally (home health or home care agencies). Next, I discuss intersectionality and theories related to the oppressive systems in which direct care workers live and work that although were not specifically highlighted in the analytic chapters of this dissertation, are indeed important to understand direct care workers' experiences. Lastly, I note specific implications of this dissertation including policy and practice changes necessary for structural level change to better support the direct care workforce.

II. Summary of Findings

In chapter three, I use a quantitative content analysis of online job advertisements to explore the connection between emotional labor and compensation for home health aides specifically. I found that over half (57%) of job advertisements in the analytic sample (n=312) did not provide a living wage according to MIT's Living Wage Calculator. Using linear probability models, I found that there is no statistically significant difference between pay rates listed by home health agencies requiring emotional labor and home health agencies not requiring emotional labor while holding education, experience, and licensure requirements constant.

Stratifying the data by home health agency/company size (1,000 employees or less and 5,000 employees or more) also yielded no statistically significant results. These findings expand upon existing literature and suggest that home health aides are undercompensated for their work regardless of agency size. Findings from chapter three are important, as they provide evidence for the need for fair compensation for home health aides across the U.S. using unique methods.

In chapter four on blurring boundaries, I argue that direct care workers experience the blurring of personal and professional boundaries. Through qualitative interviews, it is evident that direct care workers often experienced blurring boundaries, sometimes as a result of intrinsic motivations for joining this workforce. These blurred boundaries create space for both close relationships with clients and yet also creates space for exploitation such as wage theft and performing additional unpaid labor. Direct care workers occupy a unique space in their roles, perceived and treated at times as family members, which requires new perspectives on the fluidity of boundaries for this critical workforce. This chapter is important as it highlights the tensions of personal and professional boundaries for direct care workers providing care and services in individuals' homes.

In chapter five, I discuss direct care workers' lived experiences during the COVID-19 pandemic. Using semi-structured qualitative interviews, I discuss how direct care workers experienced fear and risk calculations as they shifted between interactions with their clients and their family members and were essentially caught in between these two groups. This notion of being in between continues to build on themes from chapter three regarding blurring boundaries and the ways in which intrinsic motivations open opportunities for forming close relationships and also for exploitation. This chapter also details how direct care workers wanted more recognition for their work as frontline workers during the COVID-19 pandemic and also an acknowledgement of their critical role in the health care team for older adults. Chapter five details the lived experiences of direct care workers providing in home care and services during the COVID-19 pandemic, which is important to explore to better support this workforce.

In chapter six, I argue that direct care workers are vulnerable to and experience disenfranchised grief when their clients die. This process occurs because the social construction of their grief is not perceived as legitimate and is further delegitimized by a lack of agency support or acknowledgement. Using in-depth interviews, I explore how direct care workers often form close, family-like bonds with their clients and yet do not receive similar family-like support when their client(s) die(s). This notion of being perceived as part of the family at times, and at other times not being seen as family continues the thread of blurring personal and professional boundaries. In this chapter, I argue that home health and home care agencies must implement mechanisms to better acknowledge and support the direct care workers that experience grief, such as peer-support groups, paid bereavement leave, and mental health coverage under insurance policies.

III. Implications

This work has several implications which fall into two main categories 1) sociological implications and 2) public health implications including structural, organizational, and policy change to bolster support for the direct care workforce. One major implication of this work is that it challenges typical narratives that bifurcate direct care workers' experiences. As previously discussed, literature often reflects opposing narratives around carework, typically discussing the challenging physical, emotional, and social work of direct care workers or discussing close, family-like relationships between direct care workers and clients. Spotlighting positive or negative experiences and consequences of care work does not capture a complete picture of nuance and complexity that direct care workers experience, and I found that they occupy a more complex space, often experiencing blurring personal and professional boundaries. This dissertation demonstrates the importance of leaning into the complex, nuanced lived experiences rather than pulling apart positive and negative aspects of this work. This is especially important for future research for this workforce to continue to incorporate direct care workers' complex experiences and challenge notions of spotlighting either positive or negative aspects of this work.

Additionally, I suggest re-framing the concept of blurring boundaries not necessarily with a negative connotation, but instead supporting the fluidity of boundaries as a more neutral term. We could also use strengths-based models and language regarding this concept to better support direct care workers in individual homes and re-frame the fluidity of boundaries. Lastly, I have found through this dissertation that the notion of disenfranchised grief should be expanded as what I call institutional disenfranchised grief. This concept expands the theory disenfranchised grief, which is typically only discussed at an individual/personal/micro level, and further proposes that disenfranchised grief can happen at an institutional level wherein direct care workers' experiences of grief are often delegitimized and not acknowledged or supported by institutions such as home health and home care agencies.

There are many implications for structural, organizational, and policy change to better support direct care workers providing care and services to older adults in individual homes. One major suggestion is raising the pay rate across the U.S. for direct care workers. Another suggestion is implementing health insurance for all direct care workers, and mental health coverage under insurance. Additionally, some direct care workers shared that they did not have paid sick leave or retirement benefits as this work is often not considered to have enough hours/years to meet national federal requirements. Further, many direct care workers noted that they were not paid for mileage even when they were required to do errands, transport clients to doctors' offices, etc. To address this, there should be a paid mileage program for all direct care workers providing in home care and services.

Home care or home health agencies could implement programs to better support direct care workers providing care and services in individual homes. Home care and home health agencies could implement peer-support groups at an agency level as a way to improve social support and encourage relationship/team building among co-workers (especially as this occupation is largely solitary). Agencies could also create a more thorough onboarding process for direct care workers that discuss challenging topics like navigating personal and professional boundaries, encountering and experiencing grief, etc. Another implication for this work is implementing training opportunities for direct care workers on a myriad of topics but especially including challenging situations featured in this dissertation such as grief and loss, additional labor, etc. Lastly, it is important to acknowledge that many people join this workforce due to intrinsic motivations, and how this may open opportunities for close, reciprocal relationships and also for exploitation at a client and institutional level.

IV. Limitations

There are a few limitations for this work, namely that intersectionality and structural and intersecting oppressions were not as thoroughly explored in the analytic chapters. Though these theories were important to discuss and highlight, participants did not discuss discrimination and microaggressions at length. This might have been due to my own positionality as a white woman, or because all interviews were conducted over the phone and perhaps participants did not feel comfortable discussing this topic. It may also be the case that participants found other topics more salient at the time, such as experiences during the COVID-19 pandemic or experiences of grief. There was limited engagement regarding intersectionality and structural oppression as analytic frameworks in this dissertation given that the topic was rarely discussed, which may be a limitation.

V. Future Directions

Future directions should continue to explore direct care workers' experiences providing care and services to older adults in individual homes. For example, future studies could inquire more specifically about and center questions around racial discrimination and oppression at both an institutional and individual level, especially as participants in this dissertation rarely discussed this topic. Other research could explore whether and if so, how direct care work in individual homes have changed as a result of the COVID-19 pandemic. Yet other research could explore the use and availability of training programs for this critical workforce.

In future research, I hope to explore mental health for direct care workers in more depth. This work was not specifically focused on mental health, and instead explored other important topics. In the future, I would like to explore more specific questions about mental health for the direct care workforce at both an institutional and individual level.

One direction I would like to pursue using this data from the dissertation is on finding meaning for this workforce. Specifically, I asked participants "what does this work mean to you" and I did not have time or space in this work to write the results from that data. Participants gave in-depth responses and discussed what it means for them in terms of their identity, in terms of job stability, in terms of feeling like it was a calling, etc. This topic is not often discussed in existing literature, and I am very interested in writing a manuscript on the finding meaning for direct care workers around their work and the important role it has in their lives.

VI. Concluding Remarks

In this dissertation, I found that home health aides are undercompensated for their labor, especially for emotional labor, adjusting for geographic contexts in the U.S. Additionally, I found that the unique care setting of individual homes coupled with intrinsic motivations for participation in the direct care workeforce contribute to this notion of boundary blurring and opens opportunities for reciprocal relationships with clients and also for exploitation at institutional and individual levels even if unintentional. Through this work, I also found that blurring boundaries occurred especially throughout the COVID-19 pandemic, and that direct care workers experienced a lack of appreciation and recognition for their work during this time. Lastly, I found that direct care workers and clients form close, family-like relationships and yet do not receive or have access to family-like support systems when their clients die. I argue that direct care workers are vulnerable to and experience what I call institutional disenfranchised grief due to the social construction of their relationship with clients that does not see the grief as legitimate and further erasure and/or delegitimization of their experiences by a lack of agency/institutional support. Overall, it is imperative that we recognize the complexity of direct care workers' experiences in order to better support this critical workforce.

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APPENDIX

Script for Eligibility

(Conducted over the phone)

A greeting, such as:

- Hello, thank you for your interest in this study.
- Hi there, thank you for calling about your interest in this research.

Determining Eligibility

- Are you 18 years or older? Yes or No
- Are you paid for your work as a direct care worker caring for older adults in the US? Yes or No
- Do you read, write, and speak in English? Yes or No
- Do you primarily care for non-family members? Yes or No

If all are answered Yes, then they are eligible for the study.

- Continue to schedule an interview date, place, and time.
- Or, continue to conduct an interview over the phone and obtaining consent.

If any of the questions are answered with a No, then they are ineligible for the study. The following is the script if someone is ineligible:

- I'm sorry, but at this time you are not eligible for this study. Thank you very much for your interest in this research. Goodbye.
- You are ineligible for this study but thank you for your interest. Have a nice day, goodbye.

Reddit Script

I plan to contact the moderators of certain pages on Reddit to see if they will post a copy of the flyer attached to this application.

I will say something to the effect of:

Hello, I am a graduate student at UCSF and I am interested in interviewing direct care workers who work with older adults in the US about their experiences of work during the COVID-19 pandemic. The flyer is attached. Could you please post this to the sub-Reddit so that people can contact me if they are interested in participating?

Information Sheet

We are asking you to take part in a research study being done by Brittney Pond and Dr. Kristen Harknett at the University of California, San Francisco.

We would like to interview you to learn more about your experiences working as a home health aide during the COVID-19 pandemic. The interview will last about one to two hours. This interview will be audio recorded with your permission. The audio recording will be deleted one year after interview completion. You will receive a $40 gift card via email as compensation for your participation.

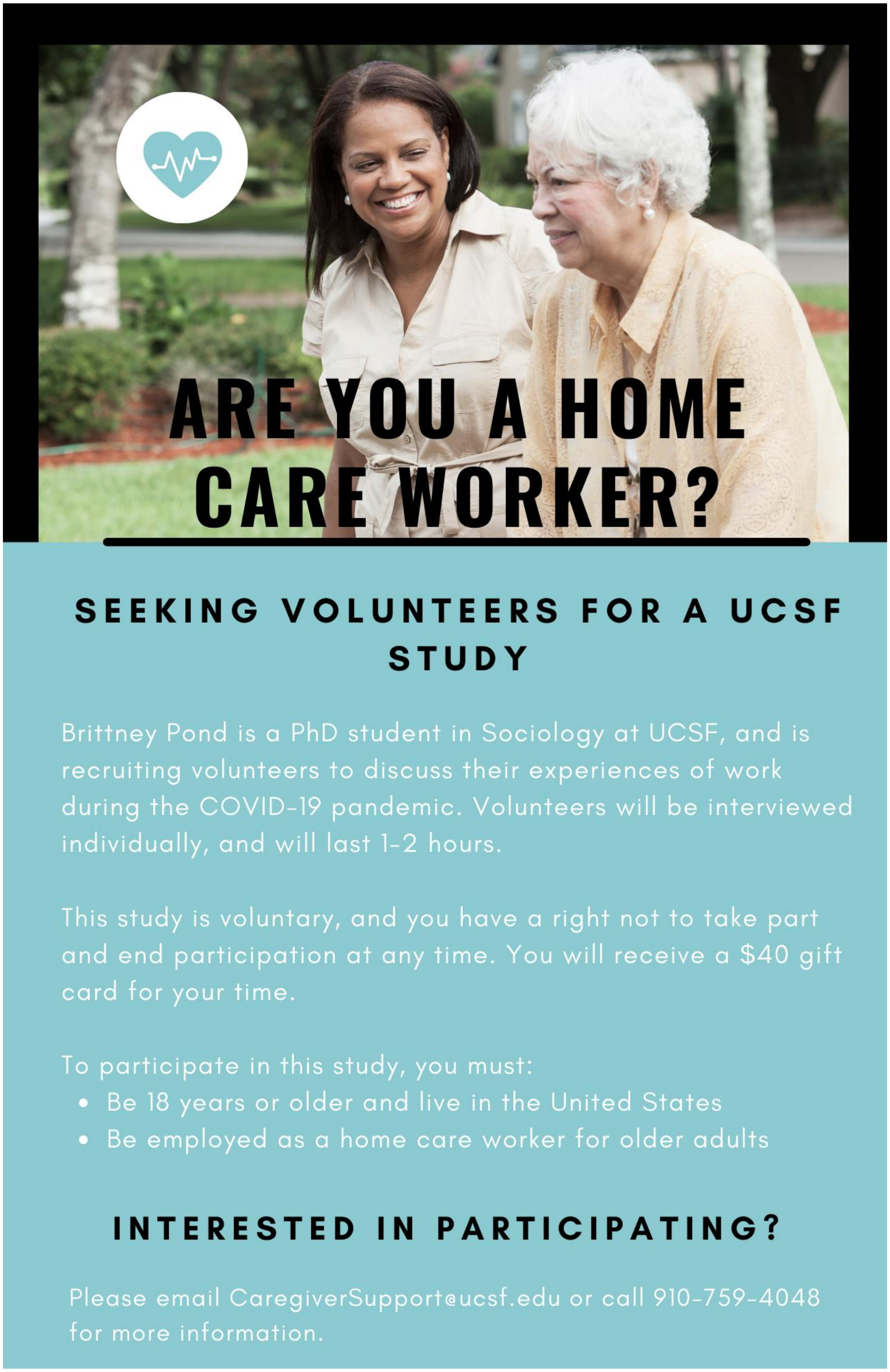
You can skip questions that you do not want to answer or stop the interview at any time.

We will keep the data we collect confidential, and we will not share your personal information with anyone outside the research team.

Being in this study is optional. Please tell the researcher if you do not want to participate.

You may choose to participate in a verbal or audio diary in which you free-write or talk about your daily experience at work based on a few prompts. This can be sent via email from audio recording such as voice memos or with a recording device. Audio diary recordings will be deleted one year after diary completion. This is an optional component.

Recruitment Flyer



ARE YOU A HOME CARE WORKER?

SEEKING VOLUNTEERS FOR A UCSF STUDY

Brittney Pond is a PhD student in Sociology at UCSF, and is recruiting volunteers to discuss their experiences of work during the COVID-19 pandemic. Volunteers will be interviewed individually, and will last 1-2 hours.

This study is voluntary, and you have a right not to take part and end participation at any time. You will receive a $40 gift card for your time.

To participate in this study, you must:

- Be 18 years or older and live in the United States
- Be employed as a home care worker for older adults

INTERESTED IN PARTICIPATING?

Please email CaregiverSupport@ucsf.edu or call 910-759-4048 for more information.

Interview Guide

Main Topic Questions	Probing Questions	Notes
What does a typical day look like for you?	- What are the tasks you do in a day? - How many people do you typically care for/caseload? - Are working hours predictable, scheduling?	
Why did you choose this kind of work?	- Positives –most satisfying part of your work, and what does it mean to you? - Negatives – any challenges? - Occupational health issues (i.e. physical demands of the job) - Mental health aspects	
Do you have any health conditions and how does this impact your work?		
What does it mean to be a Direct Care Worker?	- Tell me more?	
What has your experience of work been like during the COVID-19 pandemic?	- How did it feel? - What challenges did you face? - What were your worries during this time? - Can you think of any positives that came out of this time? - How are you doing now? - Has anything changed in your experience in the early days of the pandemic vs. currently?	

Do you feel like you have the support you need?	- At work? - At home? Self-care?
Where do you find support and where do you wish you had more?	- What do you do to relax? - What are barriers to this?
Where do you find community?	
What identities are important to you in your working life/everyday life?	- Can you tell me about a time when your identity has been important or impacted your work?

Is there anything else you would like to talk about that I did not mention, or that we did not discuss?

Mental Health Matters Handout Sheet

MENTAL HEALTH MATTERS

IF YOU OR SOMEONE YOU KNOW IS IN CRISIS OR NEEDS HELP, PLEASE SEE THE RESOURCES BELOW:

- If you are in an emergency, please contact 911.
- National Suicide Prevention Hotline: 1-800-273-8255
- Alzheimer’s Association Helpline: 1-800-272-3900 or visit https://www.alz.org/help-support
- Mental Health America: https://www.mhanational.org/
- Crisis Textline: Text MHA to 741741
- Caregiver Action Network - Help Desk: 855-227-3640 or visit https://caregiveraction.org/covid-19
- Anxiety and Depression Association of America: https://adaa.org/find-help

Publishing Agreement

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Brittney Pond____________________ ______4/30/2024__________
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Author Signature Date