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An Intersectional Perspective on the Role of Workplace Policy Among Employed Female Caregivers During the Coronavirus Pandemic

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An Intersectional Perspective on the Role of Workplace Policy Among Employed Female

Caregivers During the Coronavirus Pandemic

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A Dissertation

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by

Jessica King McLaughlin

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Advisor: Leslie Hasche, MSW, PhD

Abstract

Providing care for an older adult while working can be challenging, often leading to caregiver burden. The socioenvironmental context of the coronavirus pandemic creates additional complications for working caregivers. Women, who are the majority of informal caregivers, face unique stressors in the workplace (McKinsey & Company, 2019; Carnevale et al., 2018). Prior to and during the coronavirus pandemic, workplace policies have offered the potential of support, yet more information is needed on how working female informal caregivers of older adults of diverse identities receive, interpret, and experience these policies amidst the context of the pandemic. This study uses a phenomenological qualitative approach to explore caregiver burden from emotional, financial, physical, and work-related perspectives and caregivers' experiences of relevant workplace policies. Interviews with 29 working female caregivers, ranging in age from 27 to 75 years old, were held between February and April 2021 via Zoom video conferencing technology. Analysis of written transcripts revealed the many facets of burden caregivers were facing during the pandemic, with an emphasis on the negative emotional impacts of this burden. Workplace policies that centered around flexibility and compensated workplace leave were identified as advantageous. Findings also pointed to the importance of a supportive supervisor and overall workplace culture as being critical factors that facilitated the use of accommodative workplace policies. From an

intersectional perspective, a caregiver's job status and rank in the workplace contributed to access to supportive workplace policies. This study highlights the necessity of creating more caring workplace cultures that conceptualize workers in the greater context of their lives outside of work. Future research would benefit by including a diverse sample of caregivers across various socioeconomic, educational, gender, and racial strata, including a quantitative component of caregiver burden, and querying more specific details of the caregiving scenario. Recommendations for workplace policies include the federal passage of a paid leave bill, tailoring workplace benefits to the needs of an organization's workforce, allowing flexibility for all workers, and creating universal access to accommodative workplace policies to all employees at an organization, regardless of their job status.

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To my husband Gordon, the past 4+ years have arguably been some of the most challenging of our relationship, with job changes, moves, a political campaign, the death of one of our dear friends, a pandemic, and too many late nights to count. I could not have done this without your support and belief that I would eventually finish this opus. Thank you for allowing me the time to focus solely on this and believing in me, especially when I doubted myself.

To my family, without whom I would not be where I am today. To be sure, this road has been bumpy and uncertain, but you allowed me the space to grow, learn, and figure it out on my own, even when that was likely very hard to do. Thank you for championing me and not asking *too* many times when I would be "done"!

And finally, to the over 30 million working informal caregivers of older adults in the United States, you are often unrecognized for the vital care you provide. I honor and am humbled by what you do to care for others. This dissertation is dedicated to you.

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Chapter One: Statement of the Research Problem and Major Questions

Introduction

Women report significant struggles in balancing work and caregiving roles, often leading to caregiver burden. This caregiver burden is manifested emotionally, physically, and financially. Workplace policies, such as flexible working hours, the ability to work remotely, and paid leave, may alleviate many of the difficulties that working female caregivers face. However, little is known about how workplace policies impact working female caregivers' level of caregiver burden differentially by identity and if they address caregiver burden.

The differential impacts of caregiver burden on working female caregivers must be viewed within the current societal environment of the coronavirus pandemic. During the first eleven months of the pandemic, between February 2020 and January 2021, over 2.3 million women left the workforce, many citing caregiving reasons (Connley, 2021; Ewing-Nelson, 2021; Gitis, 2021). Though women are re-entering the workforce (Hegewisch & Mefferd, 2021; Padilla, 2021), women's jobs on payroll still lag behind men's jobs. As of October 2021, women's jobs on payroll are 2.9 million less than they were prior to February 2020, while men's jobs on payroll are only 2.1 million less (many individuals work more than one job so jobs on payroll are not equivalent to the number of people in the workforce; Lutz, 2021). This is notable because women's jobs on payroll were greater than the number of men's jobs on payroll in January 2020 for only the

second time in recorded history (Horsley, 2020a). The months that women spend away from the workplace and without a paycheck will have detrimental impacts on savings and long-term financial potentials. This may increase financial burden, as well as other types of burden among working female caregivers, which may vary in severity based on the caregivers' identities. For example, the financial impacts of the pandemic are predicted to negatively affect minoritized women to a greater degree than white women given historical disparities in pay and income spurred by economic segregation and racism (Bovino & Zafar, 2021; Connley, 2021; Fitzhugh et al., 2020; Hegewisch & Mefferd, 2021).

Some evidence points to significant burden among working caregivers during the pandemic (Rosalynn Carter Institute for Caregiving, 2020), however, no information was provided in this report about differences based on identity. Given the many workplace and policy changes since the pandemic began in March 2020, it is necessary to gather a complete picture of caregiver burden and the role of workplace policy in the daily lives of diverse working female caregivers during this time.

Caregiving Defined

Though estimates vary, approximately 16.8% of the adult American population, or 41.8 million adults, provides informal care for an adult over the age of 50 who is unable to independently care for themselves (NAC & AARP, 2020). Caregivers provide assistance in various capacities, such as helping with household tasks (e.g., laundry, cleaning, cooking, grocery shopping, transportation), activities of daily living (ADLS; e.g., bathing, dressing, feeding, toileting, transferring), health and medical care (e.g.,

medication administration, wound care); care coordination (e.g., communication with healthcare professionals, arranging medical appointments, ordering prescriptions, talking to insurance companies), and proxy legal matters (e.g., managing financial affairs, involvement in medical or care decisions; Feinberg, 2018; Population Reference Bureau, 2016; Schmepp, 2016). Caregiving can be both paid work that is done professionally by someone who is hired for this role or can be done informally, typically without pay, by family members and loved ones who have a pre-existing relationship with the care recipient. This dissertation will be primarily concerned with the latter category of caregiving, informal caregiving, hereafter simply referred to as "caregiving."

Who are the caregivers?

Women have historically held the role of family caregiver (Brody, 2004, Schulz & Eden, 2006; Yee & Schulz, 2000), a gendered phenomenon shared across many cultural and ethnic groups. The most recent data estimates indicate that approximately 61% of caregivers are female (NAC & AARP, 2020), though this percentage may increase based on the conditions that require care. Typically, female caregivers care for more medically complex care recipients and those needing more intensive care (Dardas et al., 2019; Pei et al., 2017; Pinquart & Sorenson, 2006; Skira, 2015); as many as 78.6% of dementia caregivers are women (Wolff et al., 2017). Moreover, female caregivers also spend more time providing care overall than male caregivers do (Pinquart & Sorenson, 2006).

Eighty-two percent of caregivers are between the ages of 18-64; the "average" caregiver is 49.4 years old (NAC & AARP, 2020). Nearly a third (29%) of caregivers are

"young adult" caregivers, described as those who are age 39 and younger and part of the

so-called "Millennial" and "Gen Z" generations (Taylor; 2014; NAC & AARP,

2020). Given these ages, the majority of caregivers work outside of their caregiving

duties; 60% of caregivers work full-time (defined as a minimum of 40 hours per week)

and an additional 15% work between 30-39 hours (NAC & AARP, 2020). Regardless of

race or ethnicity, caregivers are more likely to be working than not (NAC & AARP,

2020). Working caregivers work an average of about 36 hours per week (NAC & AARP,

2020). The proportion of caregivers who work has been increasing over time as women's

labor force participation has grown (Schulz & Eden, 2016).

Caregiver Burden

"Caregiver burden" is a broad term that speaks to the detrimental effects of

caregiving on caregivers. Some have described it as the "workload" associated with

caregiving (Juratovac & Zauszniewski, 2014, p. e189), while others state that caregiver

burden is often related to the level of unmet need that a caregiver may experience

(Campione & Zebrak, 2020). Gender has been found to be a highly significant predictor

of burden for caregivers (Schrank et al., 2016), with women experiencing significantly

more burden than men in their caregiving duties (Gupta et al., 2016; Pinquart &

Sorenson, 2006; Riffin et al., 2019). The effects of this burden can be experienced

emotionally, physically, financially, and socially (George & Gwyther, 1986). Caregivers

who also hold paid employment in addition to their caregiving duties may experience

exacerbated effects of this burden; that is, they may experience "work burden" due to

caregiving and its interference with work. This research focuses specifically on the

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emotional, physical, financial, and work aspects of caregiver burden on working female caregivers.

Identity-Based Differences in Caregiving

As the United States population grows more diverse in racial and ethnic representation over the years due to factors like immigration (Frey, 2020; Population Reference Bureau, 2000), so too does the caregiver subset of the population (NAC & AARP, 2020; Wolff et al., 2017). According to the National Alliance for Caregiving and AARP (2020), the racial and ethnic demographic breakdown of caregivers closely approximates the racial and ethnic demography of the U.S. population at large (United States Census Bureau, 2019). Sixty-one percent of caregivers identify as white, non-Hispanic, 14% identify as African American, 17% identify as Hispanic, and 5% identify as Asian American, and 3% are described as "Other" (NAC & AARP, 2020). Yet, many of the population-based studies on female working caregivers have participant samples that are predominantly white (e.g., DePasquale et al., 2016; 2018a; 2018b; 2019; Hopps et al., 2019; Stoiko & Strough, 2019).

Minoritized caregivers have a higher likelihood of having an unmet caregiving need than white caregivers (Campione & Zebrak, 2020; Navaie-Waliser et al., 2001). Specifically, Black caregivers are four times as likely to report an unmet caregiving need than white caregivers when caregiver burden is high (Campione & Zebrak, 2020). Despite this, Black caregivers and other minoritized caregivers derive more positive benefit from caregiving than white caregivers (Cook et al., 2018; Fabius et al., 2020; Moon et al., 2020; Pinquart & Sorenson, 2005; Vickrey et al., 2007) and are less likely to

report emotional difficulties from caregiving than white caregivers (Fabius et al., 2020; Namkung et al., 2017). One study found that minoritized caregivers are more likely to report that caregiving provides them with new skills and that they are "making an important contribution to the care" of their loved one (Reinhard et al., 2019, p. 24). However, other research has found that Latine/Latinx/Hispanic and Asian caregivers may experience greater levels of emotional distress than white caregivers (Pinquart & Sorenson, 2005).

In terms of the physical effects of caregiver burden, the extant literature has remarked on racial and ethnic differences among caregivers. One meta-analysis of 116 articles found that Asian, African American, and Latine/Latinx/Hispanic caregivers had worse health outcomes than white caregivers (Pinquart & Sorenson, 2005). Rote and her co-researchers (2019) found that Mexican-origin caregivers rated their health more poorly than both white and African American caregivers. However, Badana and colleagues (2019) found that there were not any significant main or interaction effects of race on physical strain in a sample of Black and white caregivers.

From a financial burden aspect, Black caregivers struggle more financially than white caregivers (Fabius et al., 2020; Pinquart & Sorenson, 2005; Welch et al., 2005). Black/African American caregivers had twice the likelihood of white caregivers to have struggled to pay for care for their loved ones during their last year of life and were more likely to have used a sizable portion of their savings to afford care for their loved one (Welch et al., 2005). A qualitative study on Latinx caregivers found financial insecurity

as a pervasive theme among respondent data (Corvin et al., 2017). Contrary to this, Willert and Minnotte (2019) found that race did not significantly predict financial strain among their diverse sample of caregivers, however, it is unknown what the racial identities of caregivers in their study were, as they only differentiated race among caregivers by describing them as white and "non-white." Further exploration into racial and ethnic differences in caregiver burden is necessitated.

The extant research literature on variations in the experiences of working caregivers by race is limited. However, racial and ethnic disparities in the workplace exist, which can compound burden that working caregivers of color may already face. Among all workers, women of color face the greatest gaps in wages, with Latine/Latinx/Hispanic women earning the least out of any demographic group. Latine/Latinx/Hispanic women are paid 55 cents for every dollar that a non-Latine/Latinx/Hispanic white man is paid, resulting in a nearly $30,000 annual income difference (National Partnership on Women and Families, 2021). Beyond differences in income, there are other barriers that women of color face in the workplace before any caregiving considerations are factored in. Women of color are the least likely to hold executive positions at companies and promoted within their companies at the slowest rate; among all workers, Black women are promoted the least (Thomas et al., 2020). Status and job title within the workplace often confer power and autonomy to those who hold higher workplace positions (Campos-Castillo & Ewoodzie, 2014), allowing those in higher status positions to be more flexible with their work time (Kossek & Lautsch, 2017).

Since the start of the pandemic in March 2020, Black women are twice as likely as women overall to report that they do not feel supported in their identities at work (Thomas et al., 2020). Black and Latine/Latinx/Hispanic workers are more likely to work in jobs with schedule fluctuations, resulting in a lack of control in the workplace (Shakesprere et al., 2021). Further, Black women have less autonomy over their job roles and face higher rates of discrimination in the workplace (Shakesprere et al., 2021). In terms of benefits, workers of color are less likely to have employer-sponsored insurance, retirement accounts, and paid leave (Shakesprere et al., 2021). Without access to helpful benefits and policies that other workers have, women of color are at a much greater disadvantage when trying to manage both work and caregiving.

Workplace Policy Responses to Caregiving

The implementation of federal workplace policy has the potential to alleviate caregiver burden (Fuller & Raman, 2019; Scharlach, 1994) with no direct action required on the part of caregivers themselves. For example, the Family Medical Leave Act (FMLA), passed in 1993, mandated employers of minimally 50 employees to provide 12 weeks of job-protected unpaid leave to employees who need to take a leave of absence to care for themselves or a family member (child, parent, or spouse; Institute for Women's Policy Research, 2018; United States Department of Labor, 2012). Advocates and progressive politicians are focused on changing FMLA to stipulate that family leave be a *paid* benefit workers can use to take time off work to provide family care (Donovan, 2019; National Partnership for Women & Families, 2020). However, women are overrepresented in low- and minimum- wage, hourly, and part-time work (Metropolitan

Policy Program at Brookings, 2019; United States Bureau of Labor Statistics, 2020b) - all types of jobs that are the least likely to provide job benefits like FMLA leave (Acosta & Wiatrowski, 2017). Fifty-eight percent of working caregivers report having access to paid sick days (NAC & AARP, 2020), which is significantly less than the 78% of the general population who report having access to this same benefit (United States Bureau of Labor Statistics, 2021).

Experimental programs aimed at reducing caregiver burden have taken root throughout the country. One such program that was created in 1995 and established by the National Institute on Aging and National Institute on Nursing Research, Resources for Enhancing Alzheimer's Caregiver Health (REACH) targets the wellbeing of family caregivers for those with Alzheimer's in locations across the country (Schulz et al., 2003). Its second iteration achieved statistically significant outcomes in reducing caregiver burden (Lykens et al., 2014). However, in interventions like these, the onus is typically on caregivers to engage in interventions to relieve their burden through services like support groups and educational classes.

Employers may offer a variety of workplace policies as avenues to mitigate caregiver burden for working caregivers, such as flexible work schedules, job-protected and paid leave time, job-sharing, and remote work options (Blair-Loy & Wharton, 2002; Brown & Pitt-Catsouphes, 2016; Chesley & Moen, 2006; Earle & Heymann, 2011; Feinberg, 2018; Fuller & Raman, 2019; Greenfield et al., 2018; Pavalko & Henderson, 2006). However, just over half of caregivers have flexibility in their work hours (55%) and access to unpaid family leave (53%; NAC & AARP, 2020). Less than 40% of

caregivers have access to paid family leave (39%), resource referral and Employee Assistance Programs (EAPs; 26%), and only a quarter report that they have the option of working remotely (NAC & AARP, 2020), though this percentage has changed in recent months due to the coronavirus pandemic. Hourly workers, who make up more than half of all caregivers, are less likely to have access to any of these benefits than caregivers who are salaried workers (NAC & AARP, 2020).

Differences in accessibility to workplace policies are salient when workers' race and ethnicity are considered. Latine/Latinx/Hispanic workers were less likely than all other racial/ethnic categories to have access to a flexible work schedule in 2017-2018, with white people being the most likely to have access to flexibility in their work schedules, followed by Asian and Black workers (United States Bureau of Labor Statistics, 2020a). The Bureau of Labor Statistics aggregated data from four nationally representative datasets and found that Latine/Latinx/Hispanic individuals were also the least likely to have access to paid leave for eldercare reasons; Black, non-Latine/Latinx/Hispanic workers were more likely than Latine/Latinx/Hispanic workers to have access to paid leave for eldercare but still had less access than white, non-Latine/Latinx/Hispanic individuals (Bartel et al., 2019).

The Coronavirus Pandemic and Its Effects on Working Female Caregivers

The current socioenvironmental context is germane to the discussion of differential impacts of caregiver burden on working female caregivers. Since March 2020, the coronavirus pandemic (frequently referred to as "the pandemic" in this dissertation henceforth) has indelibly impacted American society. More than 2.3 million

women left the workforce between February 2020 and January 2021(Ewing-Nelson, 2021); in the first month of the pandemic, almost 60% of the jobs that were eliminated were women's jobs in industries like service and hospitality (Horsley, 2020b). Women left the workforce at a rate that was quadruple that of men (Schneider et al., 2020), in large part due to caregiving reasons (Kashen et al., 2020; Yavorsky et al., 2021). Any workforce exit has detrimental impacts on women's savings and long-term financial potentials, with Black women facing particularly acute economic hardship during this pandemic due to layoff rates that are twice of those for white men (Fitzhugh et al., 2020; LeanIn.Org & SurveyMonkey, 2020). While much of the recent press coverage focuses on women exiting the workforce to provide childcare (e.g., Brown et al., 2021; Kashen et al., 2020; Miller, 2021; Schneider et al., 2020), little is known how burden related to caregiving for older adults has changed for working female caregivers among different racial and ethnic identities. In a recent survey, 83% of caregivers reported experiencing heightened stress related to caregiving during the pandemic than they had prior to it (Rosalynn Carter Institute for Caregiving, 2020) and almost one quarter of caregivers reported not feeling supported in their caregiving duties by their workplace during the pandemic (Rosalynn Carter Institute for Caregiving, 2020). As such, there is a need to understand the intersectional experience of caregiver burden and what role workplace policy plays in the day-to-day lives of diverse working female caregivers.

Research Questions

The purpose of this exploratory study is to investigate the impacts of workplace policy on working female caregivers' burden during the coronavirus pandemic and how

these impacts may vary by identity. These issues are framed and understood using the theoretical frameworks of role conflict, the theory of gendered organizations, and intersectionality. Two broad, interrelated research questions, informed by gaps in the extant literature, as well as the current societal context, will guide this dissertation.

1.) How has workplace policy impacted working female caregivers during the coronavirus pandemic?

2.) How do these experiences vary based on caregiver identity?

Delimitations

This dissertation centers on perspectives of female caregivers to individuals over the age of 50. However, many of the dilemmas that the caregivers mention herein are faced by people of all genders who work and provide care for individuals of any age. There has been focus on the difficulties faced by working mothers during the coronavirus pandemic in media outlets and research institutes (e.g., Miller, 2021; Schneider et al., 2020). However, an extensive discussion of these issues is outside the scope of this dissertation. Issues that other types of caregivers (i.e., parents, grandparents) face will only be referenced in the context of how it pertains to caregivers of older adults.

Professional caregivers - those who are paid to provide care and do so as their career - play a critical role in the care eco-system. In about one third (31%) of informal caregiving scenarios, professional caregivers work in tandem with family caregivers to ensure that an older adult's needs are met (NAC & AARP, 2020). However, the issues that specifically pertain to paid caregivers who provide care as a form of employment are outside the scope of this dissertation.

Finally, the terms "female" and "women" are used interchangeably throughout this exam, usually with "female" being used as a descriptor of the type of referenced individuals, and "women" being used as a noun; the same goes for "male" and "man," respectively. However, this author readily acknowledges that these two terms may not be equivalent in other contexts, given that "female" and "male" are descriptors of sex, the biological descriptor of an individual that is typically based on their genitalia and reproductive systems (Conger, 2017). "Women" and "men" are typically descriptors of gender identity, the sociocultural concept that "refers to the roles, behaviors, and identities that society assigns to girls and boys, women and men, and gender-diverse people" (National Institutes of Health, 2016, p. 1). It is important to note that both sex and gender are not binary constructs, however this research will focus on the experience of caregivers who identify as women given the lack of existing research that looks at caregiving outside of a binary view of gender and sex; none of the studies cited or reviewed in this dissertation provided any information on transgender or non-binary caregivers. The experiences, marginalization, and oppression of non-binary and transgender caregivers are critically important (Hash & Mankowski, 2017; Sackett, 2017), although outside the purview of this research.

Positionality

As my initial social work training was grounded in the clinical realm, qualitative research suits my approach to research well. I spent four years as a clinician, working with individuals and families, learning about clients' subjective realities, and trying to help clients parse meaning and insight out of life events. Padgett (2012) affirms the

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worthiness of this training for a qualitative researcher, stating that qualitative research studies "emphasize subjective meanings and question the existence of a single objective reality. Furthermore, they assume a dynamic reality, a state of flux that can only be captured via intensive engagement" (p. 3). In qualitative research, the researcher is not outside the system being observed, but rather a part of it (Padgett, 2012), just as the therapist is integrated into a client's healing journey. By engaging in qualitative research, I position myself within the research. Some may argue that this causes undue influence and bias over the data collection and analysis phases, however every researcher influences their data, be it qualitative or quantitative data, to some degree in the questions they ask and what they seek to find in their results. Research can never truly be separate from the researcher.

Past work-related experiences initially stimulated my interest in caregiving. As a hospital social worker, I spent the bulk of my days interacting with caregivers. These interactions included care coordination, emotional support, discharge planning, and occasionally tough conversations about the reality of their loved ones' medical conditions. Though the individual in the hospital bed was the identified patient for most of the medical team, my concern and focus lay primarily with the patient's caregivers. I soon realized the vital role that caregivers play in the lives of those struggling with impairing medical conditions. In this work with caregivers, I also realized that the caregivers themselves had often never considered the role that they had assumed or would have to assume post-hospitalization; it was something unexpected and unplanned.

This abrupt change in life roles and relationship dynamics was jarring and laden with stress and unknowns.

Truthfully, I had never thought much about the caregiver role prior to this work experience, despite my family having been intermittently counted among the millions of families that manage informal caregiving for their loved ones. My siblings and parents cared for my grandparents and my aunt has assumed caregiving responsibilities for my previously healthy uncle who suffered a stroke that has significantly affected his functioning. However, though caregiving had touched my family, it was never my personal responsibility, and, therefore, did not receive much of my consideration. I do not have firsthand knowledge of the burdens of caregiving or the difficulties that caregivers endure; my siblings, parents, and aunt are the only ones privy to those experiences. Yet, the caregiving members of my family have distinct structural advantages and privileges over other caregivers. They all have sufficient financial resources and were able to obtain adequate professional caregiving support to supplement their informal caregiving. All caregiving members of my family hold college degrees and were treated respectfully by professional care providers who kept them abreast of what was going on. As white people, my family never had to endure the oppression and racism inherent in the American medical system; our loved one's aches, pains, worries, and illnesses have always been believed and taken seriously. Our reality as a family navigating caregiving and the medical system this is *not* the reality of those without our privileges and advantages.

To separate myself from the experiences of the research participants in this study and to reduce the likelihood of transference from my family's experiences on to the research participants, I bracketed my thoughts and sentiments during the data analysis phase. Bracketing the researcher's thoughts is a unique approach used in phenomenological research, wherein the researcher addresses his or her experiences with the phenomenon and puts them in a separate part of the written research study so that they will not conflate their experiences with those of the participants (Creswell, 2013). This also allows study readers to know about the researcher's experiences and make judgment calls on whether they think that the researcher allowed their personal experiences to influence the research. To maintain the validity of the qualitative data, I endeavor to maintain adequate distance from what I am researching. It will be female caregivers' voices, ideas, and experiences that deserve full attention and consideration in this research.

Summary and Organization of this Dissertation

Chapter One of this dissertation introduced the research topic of working female caregivers in the context of the coronavirus pandemic and provides the research questions that guide the purpose of this study. Chapter Two presents a review of the literature relevant to working female caregivers of diverse identities, as well as explores the theoretical and conceptual frameworks undergirding this research, drawing connections between these concepts and the substantive research area. Chapter Three lays out the research methodology and analytic procedures used in this study. Chapter Four details the findings of this study and aggregated themes that emerge from the data. Chapter Five

expands upon the findings and relates them to practical policy implications and future

directions for research, while acknowledging limitations of this study. The remainder of

the dissertation contains the references and appendices sections.

Chapter Two: Review of the Literature

Introduction

      This chapter provides an overview of caregiver burden as it relates to working female caregivers, with a grounding in three theories: intersectionality, the theory of gendered organizations, and role conflict and the associated empirical literature. Caregiver burden is frequently discussed as an anathema to the caregiving experience, with an assortment of contributing factors and characteristics unique to each caregiving scenario. Various advocacy groups and organizations provide knowledge and resources for caregivers regarding interventions to ease caregiver burden (e.g., AARP, Family Caregiver Alliance, Caregiving Across Generations, National Alliance for Caregiving). These organizations identify self-help supports for caregivers, community-based interventions, as well as policy recommendations at local, state, and federal levels. Especially during the coronavirus pandemic, policy creation and reform were critical for many working caregivers. However, it is currently unknown to what extent these policies have influenced working female caregivers and how long these crucial policy changes will last. By understanding how the pandemic and the accompanying policy changes have impacted diverse working female caregivers, the present study may inform policy discussions regarding the permanency of these changes that support caregivers in the workplace.

Caregiver Burden

Background

A variety of definitions abound for caregiver burden, as the term encompasses a spectrum of negative effects that impinge on the caregiver (Mosquera et al., 2016). For purposes of this research, caregiver burden refers to the challenges that caregivers face in relation to caregiving and the negative impact these challenges have on the caregiver. The topic of caregiver burden itself has spawned numerous studies, with researchers focusing on the importance of the source of the burden (Bastawrous, 2013). This research will look specifically at four sources of caregiver burden: emotional, physical health, financial, and work.

The topic of caregiver burden arose in the research literature starting in the 1970s (Brody, 2004), even if it was not specifically named as "caregiver burden" at the time. Other common terms that are closely related to the idea of burden are the "strain" (Duxbury et al., 2011; Robinson, 1983; Yee & Schulz, 2000), "adverse effects" (Zarit et al., 1986), or the "unmet needs" (Campione & Zebrak, 2020) of caregivers. In this research, all these terms are considered synonymous. Before describing the different domains of caregiver burden, a brief review of the differential experiences of caregiver burden is provided.

Gender. Research has cited connections between gender and caregiver burden. Gender is a significant predictor and risk factor for caregiver burden (Adelman et al., 2014; Schrank et al., 2016), with women experiencing greater levels of caregiver burden then men do (Duxbury et al., 2011; Pinquart & Sorenson, 2006; Schrank et al., 2016;

Schulz & Sherwood, 2008; Swinkels et al., 2019; Riffin et al., 2019; Yee & Schulz, 2000). For women, working while caregiving predict higher levels of caregiver burden, but the same phenomenon has not been seen in men (Schrank et al., 2016). Women may experience more burden because they provide more care than men do (Martin, 2000; Pinquart & Sorenson, 2006; Yee & Schulz, 2000) and they provide care with more intimate and arduous caregiving tasks, like bathing, toileting, and other forms of personal care (Yee & Schulz, 2000).

Race and Ethnicity. There are differences in burden and perceptions of burden according to the race and ethnicity of the caregiver. One study found that the word "burden" did not resonate with Latinx/Latine/Hispanic caregivers, as they associated burden with something they were forced to do and had few positive feelings about (Mendez-Luck et al., 2020). They did, however, describe the emotional difficulties of caregiving, such as being isolated and watching the deterioration of their loved ones, as well as the physical challenges, such as feeling exhausted (Mendez-Luck et al., 2020). Another study that looked at caregiver burden through the subjective lens of the caregiver found that white caregivers were more burdened than Black caregivers (Martin, 2000), despite other evidence that Black women provide more care than white caregivers (Cohen et al., 2019). Other research indicates that women of color have a higher likelihood of having an unmet caregiving need than white women (Campione & Zebrak, 2020; Navaie-Waliser et al., 2001), but were less likely to express hardship related to caregiving (Navaie-Waliser et al., 2001).

Beyond demographic characteristics of caregivers like race, ethnicity, and gender, many features of the caregiving dynamic contribute to the rise of burden in the caregiver. Caregiving can be highly unpredictable and cause concomitant stress in other realms of life and in a caregiver's other relationships (Schulz & Sherwood, 2008). Depending on each caregiver's unique situation, multiple types of burden can arise (Pinquart & Sorenson, 2003; Schulz & Sherwood, 2008). When caregiving is combined with other societal roles, such as work and parenting roles, this burden may be exacerbated and result in role conflict, which will be discussed in a later section of this chapter.

Within caregiver research, multiple measures for assessing caregiver burden are available (Mosquera et al., 2016). Among the most well-known is the Zarit Burden Scale (Mosquera et al., 2016; Zarit et al., 1980), which was developed for dementia caregivers and asks about various aspects of the caregiver experience, such as the feelings that the caregiver has towards the care recipient and other aspects of the care relationship, including physical, financial, work, and emotional concerns related to caregiving (Zarit et al., 1980). These factors all pertain to the dilemmas of working female caregivers in this research and will be explored more in the forthcoming sections on the emotional, physical, financial, and work domains of caregiver burden.

Emotional Burden

The emotional manifestations of caregiver burden can have a detrimental effect on the wellbeing of caregivers. A 2003 meta-analysis compared caregivers to non-caregivers and looked at mental health outcomes (Pinquart & Sorenson, 2003). Researchers found that caregivers had greater levels of stress and depression and less

wellbeing and feelings of self-efficacy than non-caregivers (Pinquart & Sorenson, 2003). These same researchers found in a meta-analysis of gender differences in caregivers that female caregivers had greater levels of depression and scored lower on subjective well-being than male caregivers (Pinquart & Sorenson, 2006). Similarly, Yee and Schulz (2000) found that female caregivers experience more psychiatric symptomatology than male caregivers. From a racial perspective, analyses of the 2015 Caregiving in the US survey indicated that white female caregivers experience more emotional strain than caregivers of color (Willert & Minnotte, 2019). Results from a 2005 meta-analysis showed that African American caregivers had lower levels of depression and caregiver burden, while Latine/Latinx/Hispanic and Asian-American caregivers had higher levels of depression than white caregivers (Pinquart & Sorenson, 2005).

Working caregivers have been found to experience more insomnia, anxiety, and depression than non-caregiving workers (Hopps et al., 2017). Nurses in one study reported feelings of guilt for working when they felt they should be at home providing care (Clendon et al., 2017). Women who worked in healthcare professions who were double- and triple-duty caregivers (i.e., they provided both formal care as a nurse and informal care at home as either a parent or elder caregiver or both) reported more emotional exhaustion than their coworkers who did not provide care outside of work (DePasquale, Polenick, et al., 2018b). Other data indicate that caregiving women who work feel overwhelmed by their caregiving responsibilities; female caregivers are more likely to feel overwhelmed than male caregivers (Dardas et al., 2019).

Physical Burden

Caregivers often have poorer physical health than non-caregivers (Vitaliano et al., 2003), which reflects the ways that caregiver burden manifests itself physically. Schulz and Beach (1999) conducted a longitudinal study of 392 caregivers and compared them to 427 non-caregivers and found that the risk of mortality for caregivers who had caregiving strain was 63% greater than non-caregivers. Differences in how the effects of physical burden may vary by caregiver race are somewhat ambiguous. In a 2005 meta-analysis, Pinquart and Sorenson found that caregivers of color (African American, Latine/Latinx/Hispanic, Asian-American) had worse physical health than white caregivers, however Badana and colleagues' (2019) findings did not replicate this relationship; they found no significant main effects between the physical health of the caregiver and race. This may indicate that racial differences in caregiver health are no longer as clear-cut as they once were. The physical burden of caregiving often coincides with emotional burden. Pinquart and Sorenson (2007) found that the physical health problems of caregivers related to the mental health of caregivers and behavioral issues of care recipient, such that greater levels of depressive symptoms related to poorer physical health.

In the context of this research, it's important to look at how this physical burden may interact with work. Working caregivers had a higher prevalence of smoking and daily alcohol intake, had more diagnosed comorbid conditions, and used more healthcare services than working non-caregivers (Hopps et al., 2017). Another study found that

working caregivers had higher levels of adiposity than workers who did not provide care (Lacey et al., 2018).

Financial Burden

According to recent estimates, seventy-eight percent of caregivers report spending their own money on caregiving costs (AARP, 2021b). The average caregiver spends more than $7,200 out-of-pocket annually on caregiving expenses, which equates to nearly a quarter of the caregiver's average annual income (AARP, 2021b). These figures do not include lost wages and unpaid time caregivers may have to take out of the workforce for caregiving reasons.

The financial aspect of caregiver burden is consequential. Women lose a greater proportion of wages and retirement benefits than men when they leave the workforce ($324,044 for women vs. $283,716 for men) and leave the workforce at higher rates than men due to caregiving (MetLife Market Institute, 2011). When women leave the labor force to provide care, they may face challenges to re-entry when their caregiving duties have ceased or eased enough that they may be able to work again. Researchers have found that when women leave the workforce and later try to re-enter, their probability of being hired or receiving a job offer is very low (Skira, 2015). Women ages 62 and older face only a 1-2% probability of being offered a full-time job upon re-entry to the workforce (Skira, 2015). This has significant implications for women's financial prospects as they near retirement age (Johnson & Lo Sasso, 2006; Orel et al., 2007; Van Houtven et al., 2012), particularly when these financial concerns are combined with the costs that caregivers incur as part of their caregiving duties. Research shows that women

providing care earlier in life is linked to living in poverty later in life (Wakabayashi & Donato, 2006).

Due to the gender wage gap and wage discrimination (Carnevale et al., 2018), women earn less than men are and are more likely to hold lower-earning job roles (Carnevale et al., 2018). Caregivers who earn less money report more caregiver burden than their higher-earning counterparts (Willert & Minnotte, 2019). In general, about 16% of caregivers "describe their financial well-being as poor," (Collinson & De La Torre, 2017, p.14), with African American and Latine/Latinx/Hispanic caregivers being the most likely to describe their financial state this way (Collinson & De La Torre, 2017). Willert and Minnotte (2019) found that race had a negative association with financial burden, meaning that white women had less financial strain than caregivers of color. These findings are reflected in the 2020 NAC and AARP report, with African American and Latine/Latinx/Hispanic caregivers reporting greater financial consequences from caregiving than white and Asian caregivers. A qualitative study (Corvin et al., 2017) among Latino caregivers found that financial instability and inadequate healthcare due to a lack of health insurance exacerbated emotional concerns, such as stress, worry, and frustration.

Work Burden

For working caregivers, caregiver burden can be exhibited as work burden. Female caregivers who work report more burden than those who do not work (Schrank et al., 2016). Within workplaces, caregiving women experience higher job strain than men, which has been correlated with a higher risk of long-term sickness absence from the

workplace for women; the same phenomenon was not found for men (Mortensen et al., 2017). Women are more likely to decrease their working hours due to caregiving than men (Covinsky et al., 2001; Pena-Longobardo et al., 2021), which then may contribute to financial strain and concerns and increasing the number of interdomain transitions that working female caregivers have to make. Women who work in healthcare professions and are caregivers outside of work report more emotional exhaustion than their coworkers who are not caregivers (DePasquale, Mogle, et al., 2018a). Female working caregivers found that work often cut into the time and attention they could provide to their care recipients (Stephens et al., 1997). Caregivers report significant care-related work interruptions, such as having to take a care recipient to a doctor's appointment or take care-related phone calls at work, which has significant associations with depressive symptoms (Ang & Malhotra, 2017). Ward-Griffin and colleagues (2015) describe the experience that female professional caregivers, such as healthcare workers, have in trying to fulfill both formal caregiving duties at work and informal caregiving obligations at home as "living on the edge" (p. 68), which describes how caregivers feel when they are pushed to their emotional limits and there is little differentiation between their private and professional lives. While racial differences in work burden are less explored, one study found that African American and Latine/Latinx/Hispanic caregivers have a greater likelihood of having to reduce their working hours due to care-related reasons than white caregivers (Covinsky et al., 2001).

Theoretical Underpinnings

No singular theory can fully capture the nuances inherent in the lives of working female caregivers, and for this reason, this research rests upon the foundations of three theories. Role conflict, intersectionality, and the theory of gendered organizations help to construct a picture of the multiple forces at play that influence working female caregivers.

Intersectionality

Intersectionality refers to the multifaceted nature of identity and how multiple identities coincide, or intersect (Collins & Bilge, 2016; Crenshaw, 1989; McCall, 2005). Identity refers to recognition and definition; a way for an individual to locate oneself within social groups and find group membership and adherence. As Jenkins (2014) wrote, identification "is a multi-dimensional classification or mapping of the human world and our place in it, as individuals and as members of collectivities." (p. 7) Facets of identity that are pertinent to intersectionality are those in which power, privilege, and oppression have come in to play – examples include race, gender, sexual orientation, disability status, socioeconomic status, as well as immigration status.

Intersectionality has most commonly been applied to the realms of race and gender (Cho et al., 2013) and arose out of the realization that neither the feminist movement nor race studies fully captured the experiences of Black women; the feminist movement was usually centered around the needs of white women and the racial movement usually focused on the oppression that Black men faced (Crenshaw, 1991; McCall, 2005). Though intersectionality was initially coined to describe the lack of

recognition of experiences specific to Black women (Crenshaw, 1989), intersectionality has since been expanded to apply to any number of identities wherein privilege, oppression, and power dynamics come into play (Cho et al., 2013).

Research evidence supports intersectionality's application to working female caregivers of diverse identities. A 2019 McKinsey & Company report found that women experienced more microaggressions than men in the workplace, with Black women, bisexual women, and women with disabilities experiencing these with the greatest frequency. Additionally, Black women and women with disabilities reported less management support, fewer mentors, and unfair and biased promotional opportunities (McKinsey & Company, 2019). Women of color may report these feelings because they must balance caregiving responsibilities with work, which limit their ability to work longer hours, build work connections, and show the same gendered, masculine "dedication" to work that supervisors and managers may expect (Barzilay, 2019). Cohen and colleagues (2021) explicitly named intersectionality as the framework undergirding their research on differences in caregiving intensity among male and female caregivers who were Black, white, and Latine/Latinx/Hispanic. Both Black and Latine/Latinx/Hispanic caregivers of either gender provided more hours of care and helped with more activities of daily living and instrumental activities of daily living than white caregivers; for women, this difference held, regardless of employment status (Cohen et al., 2021). Willert and Minnotte (2019) used intersectionality as a guiding theory in their research on differences in caregiver strain by race, gender, and income. Data from 1,248 caregivers who participated in the 2015 Caregiving in the US survey

showed that women of color experienced greater financial strain than white women caregivers (Willert & Minnotte, 2019). As expected, the researchers also found that those caregivers with lower incomes also experienced more financial strain due to caregiving than higher income caregivers (Willert & Minnotte, 2019). This study, however, produced some findings that ran counter to intersectionality theory, such as that race was not significant in looking at predictors of financial strain and white women experienced more emotional strain than women of color, but the authors acknowledged in their limitations that this study was solely quantitative and this research would have benefited from qualitative data gathered from participants to "gain a richer understanding of the strain informal caregivers experience" (Willert & Minotte, 2019, p. 19), which is an increased strength of this dissertation's research.

Theory of Gendered Organizations: The Gendered Nature of Jobs

According to organizational logic, job roles are genderless and lack human identity (Acker, 1990); a job is merely a litany of tasks that must be completed. As Acker (1990) states, "the job is the basic unit in a work organization's hierarchy, a description of a set of tasks, competencies, and responsibilities represented as a position on an organizational chart. A job is separate from people" (p. 148). In this way, jobs and workplaces have been characterized as gender-neutral (Acker, 1990). As a job is devoid of humanity, the role of the worker is solely to execute job duties without interference of the other components of human life (Acker, 1990; Henle et al., 2019; Barzilay, 2019), such as familial concerns like caregiving. This supposedly "neutral" view of what a job is, means, however, that jobs outside the home are not suited for women with caregiving

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responsibilities. The theory of gendered organizations argues that jobs and the workplace are *not*, in fact, genderless, but very much gendered in favor of men. The idea of an "ideal worker" (Barzilay, 2019, p. 558) that can work unencumbered, without any responsibilities outside of work devalues caregivers and the work they do both in the workplace and at home. Further, this notion is discriminatory against women, given the disproportionate share of caregiving that they do (Barzilay, 2019) and traditional expectations of women (Williams, 2010).

It has been over 30 years since Acker first wrote about the idea that organizations are gendered in favor of men and designed to keep women oppressed. However, the principles of the theory are still relevant. Sexism often manifests itself in the gender pay gap; women are paid 82 cents, on average, for every dollar a man earns (AAUW, 2019). This figure is even less for Black, Latine/Latinx/Hispanic, Native Hawaiian/Pacific Islander, and American Indian/Alaska Native women, who earn 62, 54, 61, and 57 cents, respectively, for every dollar that a white, non-Latine/Latinx/Hispanic man earns (AAUW, 2019). Women are more likely to be considered among the "working poor," defined as those who work at least 27 weeks per year, yet still earn incomes below the official poverty level, with Black or African American and Latine/Latinx/Hispanic women having the greatest likelihood of being in this category (United States Bureau of Labor Statistics, 2020b). Women are also underrepresented in the top, highest-paid positions within professional settings (McKinsey & Company, 2019); many workplaces are still extremely gender segregated between upper-level management who earn high

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salaries and lower-level workers (Williams et al. 2012), even in the face of women

surpassing men in levels of educational achievement (Carnevale et al., 2018).

Masculine principles that guide the image of the "good worker" find their roots in

empirical literature. Studies have found that managers were typified as having more

masculine than feminine attributes (Powell & Butterfield, 1979; Schein, 1975). These

masculine characteristics are more highly valued and praised by society (Williams, 2010)

than the caring attributes of women because they have been synonymous with earning

capital, which has been the predominant barometer of objective "success" throughout

much of American history. These gender stereotypes can lead to discrimination against

women in the workplace, as women's stereotyped qualities of being more focused on

community and care is incongruent with the qualities that most typically associate with

the power-driven, individualistic qualities that leaders of financially successful

companies are expected to have (Eagly & Karau, 2002). Success has rarely been defined

by how well an individual takes care of others and caring for others is not something that

businesses with capitalistic ideals prize in their employees.

Role Conflict

For most individuals, the multiple roles they hold are defining components of

their identities and bring meaning and fulfillment to their lives. It is a general axiom that

individuals want to fulfill their roles and contribute to the perpetuation of society, which

relies on individuals' role fulfillment (Goode, 1960). This rings true for many working

female caregivers (Boumans & Dorant, 2014; Schulz & Eden, 2016). However, a

phenomenon known as role conflict can arise when the demands of these roles compete

with one another. Parsons (1951) defines role conflict as:

> the exposure of the actor to conflicting sets of legitimized role
> expectations such that the fulfillment of both is realistically
> impossible. It is necessary to compromise, that is, to sacrifice some
> at least of both sets of expectations, or to choose one alternative and
> sacrifice the other… [This has] to be adjusted by an ordering or
> allocation of the claims of different role-expectations to which the
> actor is subject. (p. 275)

Thus, it is not the nature of holding multiple roles that causes conflict; it is the

conflicting demands of these roles that can inflict angst and disquietude on the individual.

It is not the nature of being a caregiver and being employed that is the problem; the issue

lies in the interaction of these two roles and the competition for a caregiver's time,

energy, and attention (Goode, 1960; Marks, 1977) and the dynamics involved in both

roles (Greenhaus & Beutell, 1985). Parsons (1951) blamed the negative consequences

brought about by role conflict on the "malintegration of the social system itself" (p. 275),

which seems apt when looking at how women have been received and (not)

accommodated in the workplace.

Family-Work and Work-Family Conflict. The specific types of role conflict,

which are the focus of this research, are family-work and work-family conflict, two terms

used frequently in the caregiving literature (e.g., DePasquale et al., 2017; French et al.,

2018; Hoobler et al., 2009; Li et al., 2015). The directional nature of these concepts

implies how both family, which is used as a proxy term for caregiving (regardless of

whether the care recipient is in a caregiver's biological family or not) and work stressors

can interfere with each other. An example that shows when family-work conflict may

occur is when a caregiver is called while at work about an urgent health matter with the care recipient that requires the caregiver to interrupt their workday and leave work to rush to the hospital due to a care recipient's declining health. Alternatively, a work-family conflict could occur when a caregiver is home with their care recipient and their boss calls or emails and demands something work-related urgently or when a caregiver must work excessive hours (Pleck et al., 1980), which cut into their ability to provide care. French et al. (2018) write that these types of role conflict "[are] recognized as a prominent societal concern" (p. 285) due, in part, to the higher prevalence of dual-earner households in recent years; the singular societal role of "caregiver" is becoming less common.

Research that spans the past 20 years has repeatedly cited the demands of caregiving and the difficulties in balancing work with caregiving. Pavalko and Henderson (2006) studied female caregivers in the workforce and their propensity to leave the workforce after starting care work; they reported that "the challenge of balancing demands of care work and other roles remains significant" (Pavalko & Henderson, 2006; p. 360), alluding to role conflict in the family and work domains. Another study indicated that working caregivers are about 12% more likely to have a high level of work-family conflict that working non-caregivers (Zuba & Schneider, 2013). Other researchers looked at how the parent caregiver role interacted with other roles that daughters held- wife, mother to a child at home, and employee- and which roles conflict with others the most (Stephens et al., 2001). There was a significant relationship between role conflict and symptoms of depression, behavioral stress, and instrumental stress.

Hoobler, Wayne, and Lemmon (2009) explored how managers' perceptions of their employees' commitment to work varied by gender. Managers perceived greater levels of role conflict for female employees than male employees, even if, objectively, women experienced less role conflict than men. The implication of these findings is that family-work conflict, whether real or perceived, inhibits women from being viewed as committed to the workplace, which may affect promotional chances and career flourishment.

All three theories discussed here (intersectionality, theory of gendered organizations, and role conflict) deal with both subtleties and overt nature of individuals' identities that may dictate how they interact with the world around them. The identity of the caregiver is a key consideration in discussing caregiver burden and the influence the pandemic has had on working female caregivers. The next section discusses the pandemic as it stands at the time of this writing and the impacts it has had on different identity groups and how this pertains to diverse working female caregivers.

Coronavirus Pandemic

As of November 18, 2021, over 5.1 million people have died from coronavirus worldwide; 768,603 people have died in the United States alone (Johns Hopkins University, 2021). Individuals over the age of 50 have at least 35 times the likelihood of death from coronavirus as those who are under age 30, with the risk of death increasing with age; those who are 85 and older have 600 times the likelihood of death as younger adults and children (Centers for Disease Control and Prevention [CDC], 2021b). Indigenous, Black, and Latine/Latinx/Hispanic individuals are three times more likely to

have died from the disease than white people in the United States (APM Research Lab, 2020). This loss of life is profound and devastating, with structural racism and inequality playing a significant role in the demographic breakdown of coronavirus deaths (Bozarth & Hanks, 2020).

For caregivers in particular, the pandemic added a new layer of anxiety and stress as they worked to keep not only themselves healthy, but also their loved ones for whom they provide care. One known risk factor for heightened severity of coronavirus is age, with those who are age 50 and older being much more likely to be hospitalized or die from contracting the coronavirus (CDC, 2021b); these ages coincide with the ages of care recipients who most commonly require care (NAC & AARP, 2020). Oftentimes, care recipients also have medical conditions that make them immunocompromised, which puts them at even greater risk of serious illness from coronavirus (CDC, 2021b).

Many women, such as those who are essential workers, do not have the ability to work from home in their jobs and, thus, must work in public, increasing their odds of contracting the coronavirus. Black and Latina women are more likely to be working outside the home as essential workers than white women (LeanIn.Org & SurveyMonkey, 2020; McKinsey & Company, 2020), such as in residential nursing facilities, putting themselves at greater risk of contracting the coronavirus. Another study shows that Black workers are disproportionately represented in jobs that have a high potential for exposure to coronavirus and infection and an inability to physically distance at work, while Latine/Latinx/Hispanic workers are disproportionately represented in jobs where they are unable to work from home (Asfaw, 2021). For caregivers, this also means that they have

a greater risk of transmitting the virus to their care recipients (Health Service Executive, 2020; Phillips et al., 2020).

Caregiver burden may be greatly exacerbated under pandemic conditions that require the caregiver to either remain home and provide care to their loved one while trying to work or from caregivers' fear of transmitting the virus to their loved one from working outside the home (Chatterjee & Kwong, 2021; Phillips et al., 2020; Rosalynn Carter Institute for Caregiving, 2020). Further, many caregivers have less support in their caregiving duties due to the increased risk of coronavirus that accompanies allowing more people into the home (Phillips et al., 2020). Caregivers spend more time caregiving themselves to replace the care that professionals and others might have previously provided (Genworth, 2020; Phillips et al., 2020). In the UK, one study found that 70% of caregivers were providing an average of 10 more hours of care due to the pandemic (Carers UK, 2020). As has happened with many working mothers during the coronavirus pandemic (Kashen et al., 2020; Schneider et al., 2020), caregivers may have had to leave the workforce altogether to provide this additional care that others helped provide prior to the pandemic (Phillips et al., 2020).

Prior to the pandemic, women were faring better in the workforce than they had been historically. The gender wage gap was falling, the number of women in the labor force was at an all-time high, and women were being promoted to higher paid, managerial positions at an accelerated rate (Shaw & Mariano, 2021). However, the pandemic has had deep economic consequences for working women. Between March and April 2020, the unemployment rate skyrocketed from 4.4% to over 14% in a matter of

weeks (Soucheray, 2020; United States Bureau of Labor Statistics, 2020c); for women, the unemployment rate increased even more steeply, from 4% to 15.5% during this same period (United States Bureau of Labor Statistics, 2020c). It is estimated that, in total, 22.2 million jobs were lost during this time (Bartash, 2020). Jobs that were consumer-based and required in-person interaction, such as retail and restaurant jobs, which disproportionately employed women and could not be easily translated to a remote working format, largely drove this sharp decline in employment (Kochhar, 2020).

As Bateman and Ross (2020) write, "COVID-19 is hard on women because the U.S. economy is hard on women, and this virus excels at taking existing tensions and ratcheting them up." Existing inequities in employment were exacerbated. Women without a college degree were hit the hardest by job loss, with their rate of employment dropping 15 percentage points from March to April (Zamarro et al., 2020). Data show that people with less-than-a-college degree make up 65% of all caregivers (NAC & AARP, 2020). Latine/Latinx/Hispanic women experienced the biggest decline in employment, with 21% of them losing their jobs between March and June (Kochhar, 2020). Almost half (46%) of all working women worked in jobs that paid a median income of roughly $11 per hour prior to the pandemic, with more than half of Black women (54%) and nearly two-thirds of Latine/Latinx/Hispanic women (64%) being in this income bracket (Bateman & Ross, 2020). As such, many laid-off women did not have savings during this time of sudden unemployment. Women of color are even less likely to have access to savings during a time of unemployment given the significant disparities in household wealth and assets (Dettling et al., 2017).

Policy

Many working caregivers were beset by unaddressed policy needs, especially in the realm of accommodations for caregiving when the pandemic hit. The United States nearly stands alone among similarly developed countries in not providing universal sick leave for workers (Heymann et al., 2021), with more than a quarter of all U.S. employees not having access to paid sick leave in their workplace (Pichler et al., 2020); prior to the pandemic, low-wage workers were disproportionately less likely to have access to this benefit (Glynn et al., 2016). The first piece of federal legislation passed in response to the coronavirus pandemic was the Families First Coronavirus Response Act (FFCRA), which became law on March 18, 2020, and addressed the lack of universal paid sick leave (FFCRA, 2020). The FFCRA mandated up to 80 hours of paid sick leave for those who are either quarantined or diagnosed with coronavirus themselves or if they had to care for someone with coronavirus (FFCRA, 2020). It is estimated that the passage of this policy reduced incidence of coronavirus infection by about 400 cases per state per day (Pichler et al., 2020). Despite this, there has been low awareness of this policy; one study showed that only about 45% of employees knew about the policy and only 5.4% of workers made use of it (Jelliffe et al., 2021). Additionally, about 15 million employees per month need sick leave and have been unable to take it during the pandemic (Jelliffe et al., 2021), likely including many caregivers. Women's risk of working while sick due to unaddressed sick leave needs is 69% higher than men's (Jelliffe et al., 2021).

Significant income-related adaptations occurred in the face of the coronavirus pandemic due to new national policies, such as the $2 trillion Coronavirus, Aid, Relief,

and Economic Security (CARES) Act (Center for a Responsible Federal Budget, 2020), passed on March 27, 2020 (CARES Act, 2020). This piece of policy provided "Economic Impact Payments" that gave $1200 to every individual earning less than $99,000 and $500 for every child with a parent or guardian who met criteria (CARES Act, 2020) and provided loan payment relief for small businesses (CARES ACT, 2020). For those who lost their jobs due to the pandemic, existing unemployment benefits were augmented (Roll & Grinstein-Weiss, 2020). The Paycheck Protection Program (PPP) enabled eligible small businesses to continue paying employees during the pandemic, even if they were unable to open for business (Paycheck Protection Program and Health Care Enhancement Act, 2020). Other workplace policy changes increased flexibility and remote work options (Kashen et al., 2020). Given that women make up a sizable proportion of both owners and employees in small businesses, these measures likely helped many working female caregivers.

However, roll-out of some of these policies was plagued by inequities, with Black and Latine/Latinx/Hispanic households being more likely to be delayed in receiving the Economic Impact Payment from the CARES Act than white households (Roll & Grinstein-Weiss, 2020). Part-time and self-employed workers experienced more delays in receiving payments, along with those who were low income, without bank accounts, and people who did not own homes (Roll & Grinstein-Weiss, 2020) - all populations who likely struggled more with precarious finances. Furthermore, the effects of the CARES Act were temporary and alleviated economic losses only by an average of about 20% (Kaplan et al., 2020). Many people, especially those who were already

marginalized prior to the pandemic, such as low-income earners and those who are racially minoritized, are still struggling significantly, as these economic policy measures provided only temporary financial relief (Escobari et al., 2020; Qureshi, 2020).

A more recent piece of major federal legislation, the American Rescue Plan Act, was signed into law on March 11, 2021, nearly a year after the FFCRA was passed (American Rescue Plan Act of 2021, 2021). This act extended previously implemented unemployment benefits, as well as provided tax breaks for low- and middle-income earners who lost their jobs during the pandemic (Department of the Treasury, 2021). This policy delivered additional Economic Impact Payments of $1400 per person to those making under $75,000 annually, as well as $1400 per dependent (Department of Treasury, 2021). Small businesses received financial support through direct financial assistance and an allowance that enabled them to offset up to $28,000 in payroll tax responsibilities per employee per year (Department of Treasury, 2021). Additionally, small businesses were offered tax incentives if they allowed their employees to take paid sick leave while sick or quarantining (Department of Treasury, 2021). However, these measures were panned as insufficient by some (Hutzler, 2021).

Workplace Policy Prior to Pandemic

Family Medical Leave Act of 1993 (FMLA). Few workplace protections and accommodations geared towards helping working caregivers existed prior to the pandemic. The most well-known is FMLA, which mandates employers of minimally 50 employees to provide 12 weeks of job-protected unpaid leave to employees who need to take a leave of absence to care for themselves or a family member (child, parent, or

spouse; Institute for Women's Policy Research, 2018). Employees can take this leave in a single 12-week chunk or dispersed throughout the year (Crampton & Mishra, 1995). While employees are on leave, they remain eligible for all employee benefits, including health insurance (Breidenbach, 2003; Crampton & Mishra, 1995). When employees return to work, they must be provided with either their previous position or a lateral position (Asher & Lenhoff, 2001). An employee must have worked at their workplace for 12 months and accumulated 1,250 working hours for a company to be eligible for FMLA (Klerman et al., 2012). Approximately 18 million workers, or 13% of the American workforce (Klerman et al., 2012), use FMLA benefits annually (Jorgensen & Appelbaum, 2014). Between 3.4 to 4 million of these workers use FMLA to provide care for their family every year (Boesch, 2019; Klerman et al., 2012).

Despite its merits, FMLA is plagued by some key issues. More than one in four individuals who are eligible for FMLA are unaware that the policy exists and is available to them (Klerman et al., 2012). Those with minoritized identities are less likely to have knowledge of the policy; only 47.7% of individuals with family income below $20,000 and 57.3% of Latine/Latinx/Hispanic individuals are aware of FMLA and its provisions (IMPAQ International & the Institute for Women's Policy Research, 2017).

In recent years, the most glaring omission in FMLA policy has been the lack of *paid* leave. Paid leave was included in the earliest iterations of the FMLA bill, but this provision was removed so the bill would garner more bipartisan support (Prohaska & Zipp, 2011), making FMLA "a compromise bill" (Porter, 2014, p.1). FMLA was only considered as a "first step" policy (Asher & Lenhoff, 2001, p. 118) when it was passed in

1993, implying that a paid leave amendment would follow shortly after. However, this has still not happened 28 years later. Research has found that two weeks of unpaid leave from work can cause a low-income family living on the margins of poverty to lose about 4% of their annual income (Heymann & El-Dardiry, 2008). According to a DOL survey, 23% of respondents reported needing leave to care for a sick parent, however, only 13% took leave, with three-quarters of those who did not take leave reporting that they could not afford to take time off of work (Fine, 2006). Without the policies passed during the pandemic, many working caregivers would not have been able to care for their sick loved ones without losing valuable income.

Parttime Work and Associated Policies. Part-time work status is typically a subjective determination made by an employer; there is no federal standard for the number of hours that constitutes "parttime work" (U.S. Department of Labor, n.d.). The Affordable Care Act (ACA), passed under President Obama in 2010, mandates employers with 50 or more employees to offer health insurance coverage to all employees working 30 or more hours per week (Patient Protection and Affordable Care Act, 2010). Under the Employee Retirement Income Security Act (ERISA, 1974), employers must offer employees who work minimally 1,000 hours a year retirement benefits, which equates to an individual working approximately 19 hours per week. Beyond these two federal policies, few other universal protections for parttime workers exist; it is often left up to the discretion of the employer and state laws as to what benefits and protections are afforded to parttime workers.

Paid Family Leave

In recent years, the movement towards a federal paid family leave policy has gained significant momentum. Thus far, seven states (including Washington D.C.) currently have paid leave provisions in effect that supplement federal FMLA, with an additional three states having passed paid leave laws that are not yet paying out benefits (National Partnership for Women & Families, 2021). However, these state policies do not cover workers in the 40 other states without an enacted state-sanctioned paid leave mandate.

The 2021 budget reconciliation bill, also known as the Build Back Better Act, initially included a 12-week paid leave provision for workers, inclusive of those who work in the gig economy, are self-employed, and independent contractors who normally are not covered by workplace policies (Miller, 2021). However, during negotiations, the paid leave provision was cut down to four weeks (Adamczyk, 2021). At the time of this writing on November 16, 2021, the budget reconciliation bill is still in the throes of Congressional negotiation about specifics, with no firm details on which inclusions will pass.

Other Workplace Policies

A paid leave amendment to FMLA does not address all the challenges that female working caregivers face, especially in light of the pandemic. The scope of FMLA is limited to leave from work and job security. It does not address other job benefits that may be helpful to working caregivers, such as employer-sponsored and subsidized resources like eldercare and case management, a flexible work schedule, reduced work

hours, the ability to work remotely, or the ability to drop from full-time to part-time status without losing access to benefits like health insurance and paid time off (Fuller & Raman, 2019). In a survey conducted with 1500 employees who presently or were predicted to have caregiving responsibilities (inclusive of parenting and caring for young children), more than half of respondents ranked every caregiving benefit as a "very important" factor when deciding to remain at their place of employment, with referrals to caregiver providers through employee assistance programs (EAPs), paid leave, a flexible work schedule, and an ability to telecommute having the most widespread support (Fuller & Raman, 2019). Using data derived from the 2008 National Study of the Changing Workforce, Brown and Pitt-Catsouphes (2016) found that having access to flexible work options, such as remote work, changing work start and stop times, and extending the workday so a worker could work fewer days of the week, was negatively associated with perceived stress and work-to-family conflict for workers. Kossek and colleagues (2006) found that workers who felt that they had greater control over when, where, and how they worked had lower levels of depression, less family-to-work conflict, and fewer intentions of leaving the workplace.

A 2018 AARP report suggests that paid sick days could greatly benefit caregiving employees (Feinberg, 2018). Paid sick days, which are distinct from paid family leave, allow an employee to use up smaller increments of a workday to take a family member to doctors' appointments and use less time for short-term illness or hospitalizations that may impact the caregiver than FMLA or paid leave policies stipulate (Feinberg, 2018). Not only do paid sick days cut down on healthcare costs, but the provision of this benefit can

instill a sense of commitment in workers to their places of employment, reducing

turnover costs for employers (Hill, 2013). In the same vein, research has indicated that

those who perceived flexibility in their jobs have lower intentions of leaving the

workplace and higher job satisfaction (Scandura & Lankau, 1997).

Non-Workplace Federal Policy

Beyond workplace policy, professional services and supports that pay for

caregiver services exist throughout the United States, usually through Medicaid and other

publicly funded mechanisms that pay family caregivers to provide support. Medicaid-

funded home-and-community-based-services (HCBS) like consumer-directed care

programs (CDCPs) mitigate some financial burden for lower-income caregivers. These

programs allow care recipients to have more autonomy and control over their care than

they might have in a formal care facility (Kodner, 2003). However, CDCPs are scarce in

the U.S. and the criteria to qualify for them can be strict, sometimes excluding spouses

and people who reside with the care recipient from being paid as caregivers (AARP,

2020). Since these programs rely on Medicaid qualifications, caregivers and care

recipients who may be financially insecure but do not meet income qualifications for

Medicaid, are excluded. Additionally, undocumented individuals and those who are not

citizens cannot access these programs.

Beyond CDCPs, any sort of financial support for informal caregivers is limited

and, even within these programs, payment for informal caregivers is usually minimal.

The Recognize, Assist, Include, Support, and Engage Family Caregivers (RAISE) Act,

which sets out to create a national strategy that supports family caregiving in the

community, in healthcare settings, and in the workplace, was signed into law in November 2018 (Administration for Community Living, 2021). In September 2021, the first report from the Family Caregiving Advisory Council, which was established by the RAISE Act, was presented to Congress with recommendations on how best to support family caregivers and created the framework for what will become the National Family Caregiving Strategy (Administration on Community Living, 2021). Recommendations from the report include: raising awareness of family caregiving; including family caregivers as members of health care teams and in long-term services and supports (LTSS); providing services, resources, and supports to family caregivers; protecting caregivers' financial and job security; and using data and evidence-based practices to assess progress of family caregivers in the context of the National Family Caregiving Strategy (RAISE Family Caregiving Advisory Council, 2021).

In March 2021, President Biden proposed a $400 billion investment in caregiving supports as part of his $2 trillion infrastructure package, the American Jobs Plan (Graham, 2021; Poo & Rocketto, 2021). Though this investment was not a panacea (Bauer, 2021), this pledged money showed a renewed commitment to the importance of caregiving and care for older adults. However, on November 15, 2021, President Biden signed the finalized bipartisan infrastructure bill without the inclusion of any investment in the caring economy (Lobosco & Luhby, 2021). A Senate bill proposed on June 24, 2021, the Better Care Better Jobs Act, takes up the helm of some of the caregiving provisions that were cut from the infrastructure bill (Better Care Better Jobs Act, 2021; Caring Across Generations, 2021a), which have since been rolled into the Build Back

Better Act (Easterling, 2021). These provisions include $150 billion towards reducing the waitlist for services available through Medicaid for older and disabled adults, as well as increasing wages for home care workers (Caring Across Generations, 2021b).

Another bill that is in the works is the bipartisan-supported Credit for Caring Act, introduced on May 18, 2021 (Kerr, 2021). This bill would provide up to a $5,000 tax credit to certain working family caregivers by instituting a 30% credit for certain caregiving expenses that total more than $2,000 (Kerr, 2021). This credit could reimburse money spent on professional caregiving support, like respite, adult day care, home health aides, as well as home modifications, like safety rails and ramps (Kerr, 2021). This bill has received widespread support from caregiver advocacy and research organizations (Kerr, 2021). It may face easier passage than other bills pertaining to caregiving given that it is bipartisan-supported (Credit for Caring Act of 2021, 2021).

Present Study

The totality of the repercussions of the coronavirus pandemic on working female caregivers who may have already been saddled with significant burden prior to the pandemic remains to be seen. Given the constantly changing nature and slow pace of policymaking, there are many unknowns in the future for working female caregivers. The coronavirus pandemic has spurred policy change that has the potential to help, but it may be inadequate in the long-term. It is critical to understand how pandemic-related changes in policy and circumstance have affected working female caregivers through an intersectional lens. Given this, two broad, interrelated research questions guide this dissertation.

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1.) How has workplace policy impacted working female caregivers during the coronavirus pandemic?

2.) How do the impacts of workplace policy vary based on caregiver identity?

Summary

This chapter summarized the literature relevant to understanding and contextualizing this study, inclusive of the theoretical frameworks and discussion of the socioenvironmental backdrop. The two research questions guiding this study were also presented.

Chapter Three: Methodology

Introduction

This research takes a phenomenological approach towards the experiences of working female caregivers during the coronavirus pandemic. Creswell (2013) describes the purpose of phenomenological studies as getting to the "universal essence" (p.76) of individuals undergoing a certain phenomenon. Cohen et al. (2000) proposes that phenomenology is conducted to "understand another's experience" (p. 4). A key component of phenomenology is the focus on context and environment, which is integral to this research. Given the unique and unprecedented nature of the coronavirus pandemic, taking such an approach towards the impacts of workplace policy on working female caregivers during the coronavirus pandemic is logical.

Sampling and Recruitment

Research participants were recruited via purposive sampling methods. Purposive sampling involves intentional recruitment of research participants who have knowledge of a phenomenon under study and can provide pertinent information related to that phenomenon (Creswell, 2013). Purposively recruited research participants "share common experiences and these experiences comprise truths" (Guest et al, 2005; p. 75). As this study pertained to the experiences of working female caregivers during the coronavirus pandemic, sampling necessarily had to be limited to this population. However, even within this population, there was a rich diversity in caregiving

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experiences (e.g., care recipient diagnosis, distance caregiver lived from care recipient, caregiver and care recipient relationship) that contributed to a heterogeneous corpus of data.

Given the nature of the coronavirus pandemic and the dangers involved in social gatherings with individuals outside of one's own household (CDC, 2021a), all recruitment took place online. Though the scope of research recruitment that took place online likely increased due to the pandemic, online recruitment for research is not a novel concept and had been used frequently in the past (Hamilton & Bowers, 2006; Lunnay et al., 2014). Given the widespread and increasing access to the internet throughout the United States (88% of all households in the U.S. have access; World Bank, 2018), internet recruitment for this research was both practical and safe.

The main determinants for sample size usually lie in how closely the researcher plans to follow the participants (Steeves, 2000; Gentles et al., 2015) and the intensity of the experience being researched (Steeves, 2000). Given that this researcher wanted in-depth information and involvement with participants during the research, a large sample size was not necessary. However, as diverse identities were a salient factor in this research, the intended sample size needed to be large enough to ensure adequate and diverse representation. A minimum sample size of 12-20 participants was initially proposed as a goal.

This researcher received university institutional review board (IRB) approval for the study and recruitment began on January 25, 2021 and continued through March 2021. Initial recruitment efforts entailed advertising the study to various online locations, with

the aim of reaching as many working female caregivers as possible. This researcher posted a PDF flyer advertisement of the study (see appendix A) to her personal Facebook and Twitter profiles, as well as sent a copy of the study advertisement to a Slack channel created for graduate students to share resources and offer support to one another. This researcher sent messages describing the study to informal caregiver support groups on Facebook (Hamilton & Bowers, 2006) or posted messages to the walls of these groups if that was feasible. This researcher emailed professional contacts at her university and at nonprofit and advocacy organizations that serve older adults and their caregivers, such as local chapters of the Alzheimer's Association, Volunteers of America, and AARP. Additionally, this researcher cold-contacted organizations that served caregivers and had publicly listed contact information on their websites, such as the Family Caregiver Alliance and Colorado Respite Coalition. This researcher also posted an advertisement for the study on a virtual message board for a professional organization for gerontology scholars. Though not every interested caregiver indicated how they heard about the study, the aforementioned strategies generated responses from at least 13 caregivers (~45%) who ultimately participated in the study.

Using a snowball sampling technique, this researcher also encouraged participants to tell their own personal connections about the study and ask them to contact this researcher if they are interested in being involved. Through this method, at least seven research participants (24%) were identified. Four other participants (~14%) found out about the study through either email or messaging correspondence with this researcher on webinars or social media platforms or through other professional contacts of this

researcher. Three participants (~10%) did not indicate how they found out about the study.

Given that diversity is a critical part of this research, minoritized caregivers were intentionally targeted in recruitment methods. This researcher attended workshops, shared the research flyer with two Black faculty members and an Asian faculty member for distribution, contacted identity-based groups, such as Colorado Black Health Collaborative, African Americans in Gerontology, and churches via email that had primarily Black congregants, and revised the research flyer to specify targeted recruitment for caregivers of color. However, these efforts only resulted in two additional participants of color (~7%).

Given challenges with recruitment, only about one-quarter (24%; 7 participants) of the sample identified as women of color. This limitation, which is likely reflective of this researcher's identity as a white woman who had minimal pre-existing relationships with minoritized groups, was discussed extensively with the dissertation committee. The pandemic environment posed barriers to being able to build relationships within minoritized communities and engender trust in the research process - two critical steps in engaging underrepresented groups in research (Coakley et al., 2012; Otado et al., 2015). Other research suggests working with a "gatekeeper" to communities that differ from one's own identity is advantageous (Aaron, 2016). Given the historical harms committed against people of color under the guise of "research," it is necessary to build these mutual trusting relationships in communities in which this researcher is not a member and acknowledge the differences and privileges that she holds. The online environment did

not facilitate this trust-building process well. Furthermore, some Black caregivers may not want to publicly identify themselves as caregivers due to the stigma associated with some conditions that require care, like dementia (Aaron, 2016). It also could be that many caregivers of color were already overburdened with providing care and working during the pandemic and did not have the extra time or energy to participate in research.

Interested potential participants initially contacted this researcher via phone or email. This researcher either called or emailed the participants back to schedule a time for a brief phone conversation to ask screening questions to determine eligibility and to ensure that they understood the purpose of the study and what it entailed. If eligible for the study, this researcher and participants scheduled a mutually agreeable time for a semi-structured interview over Zoom video teleconferencing software. Zoom was chosen over telephone calls as the technology of choice as it enabled this researcher to view participants during the interview to observe their facial expressions and body language.

After the phone screen, this researcher emailed the consent form to participants so they would have a copy for their records. This researcher emphasized that participants did not need to sign the consent form, as their verbal consent would be requested at the beginning of the recorded interview. Forty-three female caregivers initially contacted this researcher to express interest in the study. Of these 43, three of these caregivers were ineligible because they provided care professionally and were paid for their caregiving services; two caregivers lived outside of the United States and did not provide care or work in the U.S.; one caregiver was ineligible because she was known personally to this researcher; one caregiver declined to participate once she found out more information

about the study, and seven caregivers did not follow up after this researcher responded to their inquiries about participation. In total, 29 caregivers met inclusion criteria and were interviewed for this research.

Inclusion/Exclusion Criteria

Caregivers had to meet certain criteria to participate. These criteria included any female caregiver over the age of 18 who is English-speaking, provides unpaid care (i.e., does not provide care as part of their job and does not receive sufficient funds from caregiving to live off) for an adult age 50 or older, and either currently works or has worked for pay at least part-time (minimally 20 hours per week) outside of caregiving at some point since the coronavirus pandemic began in March 2020. If a caregiver was not currently working at the time of interview, their reason for not working must have been related to the coronavirus pandemic. This included those who quit or had been laid-off during the pandemic. Given that "caregiver" was intentionally broadly defined to capture a diversity of caregiving experiences, distance caregivers were included in this study as well. Research indicates that distance caregivers face their own unique caregiver burdens as those who live geographically proximate to their care recipients (Bei et al., 2020; Douglas et al., 2016), which this researcher was interested in investigating and understanding further. As a measure to protect confidentiality, caregivers who were personally known by this researcher were ineligible for the study, though secondary connections (e.g., friends of friends) were eligible. Participants had to consent to audio and video recording of their interview.

Data Collection

This researcher met with participants over Zoom to conduct the pre-scheduled interviews. Every interview started with a verbal summary of the consent (see Appendix B), emphasizing the voluntary nature of the study and the right of participants to drop out of the study at any time, followed by verbal confirmation of consent from each participant. All parties who agreed to meet with this researcher for an interview over Zoom consented to participate in the study.

The next part of the interview involved each participant answering 15 demographic questions that queried the participant's age, location in the United States, racial and/or ethnic identity, relationship status, occupation, type of company at which they were employed (e.g., bank, university, nonprofit, etc.), number of hours typically worked in a week, highest level of education, annual household income, household size, number of children under the age of 18 living at home, relationship to care recipient, care recipient age, residential status of care recipient, and an estimate of the number of hours that the caregiver provided care to the care recipient each week. The exact questions are included in the semi-structured interview guide (Appendix C).

After the demographic information was collected, the main part of the interview began by asking each participant: "Tell me how you became a caregiver for [their care recipient]." This researcher allowed conversation and questions to flow somewhat naturally from this initial inquiry but six key topic areas were intentionally explored, as listed in the interview guide, and included: help with caregiving duties, either from loved ones or family members or professional, paid caregivers; how caregiving changed during

the pandemic; how the caregiver's workplace supported them during the pandemic; common policies available through the caregiver's workplace that may accommodate caregiving or make caregiving easier; policies or supports that the caregiver desired from their workplace that they did not provide; and impacts of the caregiver's identity on their caregiving experience.

The questions used in the semi-structured interview guide were informed by this researcher's knowledge of the extant literature and the three theoretical frameworks underlying this research: intersectionality, role conflict, and the theory of gendered organizations (Kallio et al., 2016). The intent behind the semi-structured interview guide was to build rapport between the interviewer and participant, as well as to allow for the open and easy flow of dialogue (Kallio et al., 2016). Semi-structured interview guides are highly recommended as tools to adequately capture the desired data in qualitative research (Kallio et al., 2016). Semi-structured interviews are recommended when the researcher will only have one opportunity to interview a participant once; in conjunction with a semi-structured format, it is also recommended to record the interview to give each participant undivided attention during the interview (Robert Wood Johnson Foundation, 2008).

Interviews lasted between 27 and 70 minutes, dependent on the caregiver's time and how much they had to say. The average interview length was 48 minutes, 54 seconds. Three participants emailed this researcher after the interview to share more thoughts they had about this researcher's questions after the Zoom interview had concluded.

Information from these emails was included in analysis alongside the transcripts of the recorded interviews.

After each interview, this researcher emailed each participant a $20 gift card as a token of appreciation for their participation. This researcher offered gift cards primarily to nationwide chain retailers (e.g., Target and Walmart) and grocery store chains, as well as primarily e-based vendors, such as Amazon. Three participants declined the gift cards in favor of donating that money to a nonprofit organization of this researcher's choosing.

Post-interview, this researcher updated an Excel spreadsheet of demographic data and assigned a unique alphanumerical code as an identifier that would mask the participant's identity. This researcher also imported the recorded interview to the Otter.ai transcription software for transcribing. Finally, this researcher made brief notes regarding her perceptions of each interview.

Analysis

Data analysis for this research took place after all interviews had been conducted and data collection was complete. The decision to begin data analysis after all data collection had taken place was to ensure that the researcher conducting the interviews would not be biased or base her questions on pre-existing data analysis or to confirm or disconfirm themes seen in prior interviews, though the researcher did have some memory of the previous interviews which may have influenced the questions that she asked.

Data analysis in phenomenological inquiry is intended to explain the behavior and decisions of those undergoing a specific phenomenon and clarify what characteristics and factors influence them (Spencer et al., 2003). The analysis plan frequently depends on the

type of qualitative study and the intent behind the research; however, this is not meant to confine the researcher, but rather provide guidance and structure to the analytic process (Linneberg & Korsgaard, 2019; Spencer et al., 2003). For this research, data analysis generally followed the data analysis steps outlined by Braun and Clarke (2006). Braun and Clarke (2006) recommended an inductive and iterative six-phase process to distill the data into themes that address the research questions. Their phases are: 1.) read each interview thoroughly; 2.) create initial codes by identifying key ideas and statements in the corpus of interview data; 3.) group like codes and identify themes that correspond with the groupings; 4.) assess the themes to ensure a good match between the codes and the data as a whole, creating a "thematic 'map' of the analysis" (Braun & Clarke, 2006, p.87); 5.) refine the themes by adding precise definitions and labels, keeping in mind the fit between the themes and the broader conclusions derived from the analysis; 6.) generate the analysis report (i.e., the "findings") using key direct quotes from the data, in line with the initial research questions and literature that informed the research (Braun & Clarke, 2006). Though these are six explicit steps, there may be multiple rounds of coding and reading through the data involved in each step. Braun and Clarke (2006) emphasize the importance of "immersing" (p. 87) oneself in the data through repeated readings and note-taking.

For this research, the first step of analysis ("Phase 1" of Braun and Clarke's analytical framework) included reading through each interview transcript and "cleaning" the conversation to ensure the transcribed text aligned with the diction in the Otter.ai software. Every word was not transcribed, as this level of detail was not essential to

understanding what the participant conveyed, nor were certain parts of the interview relevant to answering the research questions (Braun & Clarke, 2006; Carlson, 2010). Frequently, the conversational elements of the interviews, wherein the researcher and the participant may have shared commonalities, were not transcribed. For example, one participant had a daughter who attended the University of Denver (DU) as a PhD student, so there was discussion of DU and the vaccination clinics they were doing. This conversation helped build rapport between this researcher and the participant but was ultimately unrelated to the purpose of the study and was omitted from transcription.

This researcher knew other researchers would be reading the transcripts and helping with analysis. Given this, verbal idiosyncrasies that would not translate well to text and would impede the ability of other readers unfamiliar with the participants to comprehend what was being said were removed from the transcripts so that the core ideas of participants' statements were clear. This researcher kept an audit trail of all the steps she took in cleaning the data to document analytical steps (Carlson, 2010), as well as wrote down her thoughts as memos. These two habits continued through every round of data analysis. This researcher also noted emergent codes that appeared in the data (Saldana, 2013), though this is not the primary purpose of this step; this was only done to capture thoughts upon initial reading of the transcripts.

The next step (corresponding to "Phase 2" of Braun and Clarke, 2006) involved importing the data into NVivo qualitative data management software and developing a coding strategy that would produce useful and insightful codes that aligned with the data. As this researcher had already developed some preliminary codes from the first reading

of the transcripts, she built from these codes in initial coding (Saldana, 2013). This round

of coding involved identification of pertinent ideas and some in-vivo coding to highlight

key phrases and statements made by participants. Next, attribute coding took place,

wherein the demographic details gathered from the first part of the interviews were added

to the corpus of the data. This was done to add crucial context to each interview (Saldana,

2013). The following round of coding involved structural coding, which is a more theory-

driven approach to the data (Braun & Clarke, 2006) and used elements of the questions in

the interview guide as codes (Saldana, 2013). See Appendix D for generated structural

codes. In-vivo coding also took place simultaneously with structural coding, using the

aptly named "simultaneous coding" strategy (Saldana, 2013). The next round of coding

was emotion coding, which was intended to tap into each participant's feelings about

caregiving during the pandemic and identify the words and phrases they used to describe

caregiver burden. As qualitative data analysis is an iterative process, each round of

coding was done in multiple cycles, constantly whittling down and condensing the

number of codes by combining like codes together, as well as creating subcodes, which

function as a subset of a primary or "parent" code and lend specificity and precision to

the codes (Saldana, 2013). See Appendix E for these codes.

     The final round of this phase used evaluation coding to code the data that

participants shared on workplace policy. Evaluation coding is designed to identify

policies or policy aspects that are functioning well for participants and those that need

improvement based on the data shared by participants (Saldana, 2013; Thomas, 2006).

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For this round of coding, only data that pertained to workplace policy were analyzed. See Appendix F for these codes.

After completing these rounds of coding, this researcher clustered codes to create emerging themes. This correlates with Phase 3 from Braun and Clarke (2006) and is referred to as "theming the data" by Saldana (2013, p. 175). At this stage of analysis, it was critical to keep the research questions in mind to align findings that sufficiently addressed each question. This was also crucial in Phase 4, along with making sure that the themes agreed with the data. In Phase 5, this researcher refined definitions of the themes to thoroughly explicate them in the context of the overall research agenda, as well as created subthemes to ensure findings were captured comprehensively. Phase 6 will be addressed in the next chapter.

Methodological Rigor

A common practice in qualitative research to ensure reliability is meeting with other researchers who have coded the same data and discuss coding similarities and differences, working towards intercoder agreement (Creswell, 2013). This researcher recruited a team of two Master of Social Work (MSW) students and one recent MSW graduate to serve as research assistants to assist with coding and lend an extra layer of rigor to the analytic process. This researcher and the research assistants met approximately once a week for ten weeks over Zoom to go over codes, thoughts about the data, and coding strategies. Research assistants were instructed to code using the same coding strategies as this researcher (i.e., initial coding, structural coding, etc.) to facilitate code comparison. Using a simple consensus approach (Harry et al., 2005; Saldana, 2013),

differences in perspectives on codes and the data were discussed to resolve disagreements. The research assistants also emailed this researcher their codes on a biweekly basis so this researcher could check for consistency. Additionally, all researchers had a text chain as a research group, as well as kept in touch over email. This way, researchers could ask questions of the group and quickly get answers or clarification on the coding and analytic process. This allowed for feedback and exchange of ideas to ensure all researchers were on the same page. After each meeting, this researcher would review the data and refine codes based on the meeting discussion. These researchers helped with all rounds of coding with the exception of evaluation coding. This researcher was responsible for the final determination of codes.

In qualitative analysis, the researcher is seen as part of the analytical process rather than a separate, external entity. Reflexivity requires the researcher to have insight and engage in an internal exploration as to how their motivations and biases affect the research (Thomas & Magilvy, 2011). Creswell (2013) terms this more descriptively as "clarifying researcher bias" (p. 251) to add to the dependability and confirmability of the research (Houghton et al., 2013). After each interview, this researcher wrote down her thoughts and perceptions of how the interview went, as advised by Thomas and Magilvy (2011) as a form of confirmability. Upon initial reading and listening to the transcripts of the recorded interviews, this researcher also noted any further thoughts and ideas that arose, as well as continued to write reflective memos throughout the analysis process.

To further enhance rigor and credibility, theoretical triangulation (Carter et al., 2014; Creswell, 2013) was used to interpret and link findings to the three theories

previously cited: intersectionality, role conflict, and the theory of gendered organizations. This researcher engaged thoroughly with participants, responding to every email and query they had, as well as followed up by sending them resources connected to topics discussed during the interview. During data analysis, this researcher bracketed out her own experiences with the data to limit conflation of the researcher's perceptions and opinions with those of the participants (Creswell, 2013).

Member checking also took place, wherein this researcher re-contacted participants to make sure that the researchers' themes and interpretations of the data are reflective of participants' experiences with working and caregiving during the coronavirus pandemic. Participants were emailed a description of the main themes and their definitions after Phase 5 of analysis. This researcher explained in the email to participants that not all themes would apply to every caregiver's individual experience, but it is hoped that the themes captured the key elements and most pertinent parts of their experiences. Participants were asked to provide feedback and provide suggestions to improve the themes or recommend revisions to them. The purpose of member checking is to enhance "trustworthiness" of the data (Carlson, 2010, p.1105; Creswell & Miller, 2000) by checking in with participants to make sure that the data reflects their experiences. Six participants (20.7%) responded with feedback and affirmation of the findings.

Peer debriefing can take place using an "expert" who can "support the credibility of findings" (Houghton et al., 2013, p.14). This researcher met with a tenured professor

with extensive qualitative research experience to go over methodology and findings as a final measure of rigor.

Summary

This chapter discussed recruitment and sampling methods, the interview methods used to collect data from caregivers in this research study, as well as the steps that researchers took to analyze the data from the interviews. This researcher also described the implemented measures taken to enhance the methodological rigor of this study.

Chapter Four: Findings

Introduction

This chapter presents the findings from 29 interviews with female caregivers of older adults who were employed during the coronavirus pandemic. To address the first research question, *How has workplace policy impacted working female caregivers during the coronavirus pandemic?*, this researcher will explore how the pandemic has affected working female caregivers and their sense of caregiver burden broadly. The first section of this chapter explores the emotions that caregivers had during the pandemic and connects these sentiments to the concept of caregiver burden, as well as factors that mitigated and provided protection from feeling this burden. The second section of this chapter presents the nature and operationalization of workplace policies that impacted caregivers during the pandemic, both positively and negatively. This section delves into the workplace policies available to caregivers and both the intended and actual effects of these policies on caregivers' lived experiences vis-a-vis caregiver burden.

The second research question is: *How do the impacts of workplace policy vary based on caregiver identity?* Various facets of caregivers' identities frame differences in experiences with caregiver burden and workplace policy. Identity-based differences are acknowledged in the second section of the chapter and intersectionality is used to illustrate the implications of these differences on working female caregivers.

Some quotations from participants in this chapter have been edited for clarity and concision but meanings remain unchanged.

Sample Description

Caregiver Characteristics

Twenty-nine working female informal caregivers participated in this study. Participants ranged in age from 27 to 75 years old, with an average age of average age of 53 years old (SD = 11.3). Per the 2020 National Alliance for Caregiving and AARP report, the average age of a caregiver is 49 years old, so the average of caregivers in this study is comparable to national trends of caregiving women, both working and nonworking.

Caregivers were asked to describe their racial and ethnic backgrounds. Twenty-two caregivers were white (75.9%), four were Asian (13.8%), one was African American (3.4%), one caregiver identified as white and Native American (3.4%), and one caregiver (3.4%) did not provide a race. Two caregivers (6.9%) reported Latine/Latinx/Hispanic/Latinx ethnicity. Five caregivers (17.2%) were immigrants to the United States.

Caregivers lived in 14 states throughout the United States. Eight caregivers (27.8%) were from the Midwest, eight (27.8%) were from the Mountain West, six (20.7%) were from the Southeast, four (13.8%) were from the Northeast, two (6.9%) were from the West Coast, and one (3.4%) was from the Mid-Atlantic.

This sample of caregivers was, on average, highly educated; 72.4% (n = 21) of the sample held at least a four-year college degree, with 13 caregivers (44.8%) having earned

a postgraduate degree as well. Household incomes ranged from less than $25,000 to greater than $200,000. More than half of the sample (51.7%; n = 15) had incomes that were greater than $100,000.

The average caregiver household size was 2.8 (*SD* = .98) and ranged from one to five individuals. Nine caregivers (31%) were also providing care for a child or dependent adult under the age of 50 in addition to their caregiving responsibilities for their older loved ones.

Most caregivers (62%) worked between 31 and 50 hours per week. Five caregivers (17.2%) worked 30 hours or less per week; six caregivers (20.7%) endorsed working greater than 50 hours each week. Approximately one third of the caregivers in this sample (n = 10) worked for either a public or private university in some capacity. Seven (24.1%) caregivers worked for nonprofits and seven (24.1%) worked for a variety of for-profit companies. Three caregivers (10.3%) were self-employed, one (3.4%) was in the military, and one (3.4%) worked at a private K-12 school. Table 1 displays demographic characteristics of the caregivers.

Table 1

Caregiver Demographic Characteristics

Variable	*M* (*SD*)	*n*
Age	53.21 (11.3)	
Age Groups		
20-30		1
31-40		3
41-50		7
51-60		10

Variable	*M* (*SD*)	*n*
61-70		6
71+		2
Geographic Area		
Northeast		4
Mid-Atlantic		1
Southeast		6
Midwest		8
Mountain West		8
West Coast		2
Race [a, b]		
White/Caucasian		23
Asian		4
Black/African American		1
Native American/ Alaskan Native		1
Pacific Islander		0
Hispanic or Latine/Latinx Ethnicity [c]		2
Immigrant to the United States [c]		5
Education Level		
High school/GED graduate		1
Some college		3
Associate's degree		2
4-year college degree		8
Postgraduate		13

Variable	M (SD)	n
Other (Trade, Specialized, etc.)		1
Marital Status		
Never Married		6
Domestic Partner		0
Married		19
Separated		1
Divorced		1
Widowed		2
Household Size	2.76 (.98)	
1		1
2		14
3		6
4		7
5		1
Other Dependents Besides Care Recipient [c]		9
Income		
<$25,000		2
$25,001-50,000		2
$50,001-75,000		6
$75,001-100,000		4
$100,001- 150,000		7
$150,001-200,000		4
$200,001+		4
Work Hours/Week		
<20		1

Variable	M (SD)	n
20-30		4
31-40		10
41-50		8
51-60		4
60+		2
Company Type		
University		
Public		6
Private		3
Unknown		1
For-Profit		
Pharmaceutical Company		2
Bank		1
For-Profit		
Grocery Store		1
Law Firm		1
Retail Company		1
Tech Company		1
Nonprofit		7
Self-Employed		3
Other		
Military		1
Private K-12 Education		1

[a] One caregiver did not indicate her race.

[b] Those who reported more than one race are counted in each reported racial categorical.

[c] Indicates the number of participants answering "yes" to this question.

Care Recipient and Caregiving Situation Characteristics

The 29 interviewed caregivers provided care for 32 care recipients. Sixty-two percent of caregivers (*n* =18) provided care for their mothers, 27.6% (*n* = 8) provided care for their fathers or stepfather, 13.8% (*n* = 4) provided care for their husbands, one caregiver (3.4%) provided care for her grandmother, and one caregiver (3.4%) provided care for her son; of these, three caregivers (10.3%) provided care for both their mother and father/stepfather. The average age of care recipients was 79.6 years old (*SD* = 11.68), with a range of 50 to 102 years old. Nine caregivers (31%) provided care for ten or fewer hours on average every week, four caregivers (13.8%) provided care for between 11 and 20 hours, four caregivers (13.8%) provided 21 to 30 hours of care, one caregiver (3.4%) provided between 31 and 40 hours of care, one caregiver (3.4%) cared for between 41 and 50 hours each week, and ten caregivers (34.4%) provided care for 51 or more hours every week. Twenty caregivers (69%) co-resided with their care recipients, six (20.67%) lived less than two hours from their care recipients, two (6.9%) lived in different states and typically reached their care recipients by airplane, and one (3.4%) lived in a different country. The three caregivers who lived in different states and countries were considered "distance caregivers." Table 2 provides characteristics of the caregiving scenario.

Table 2

*Care Recipient and Caregiving Situation Characteristics (*N = 32)*

Variable	*M* (*SD*)	*n*
Care Recipient Relationship to Caregiver		

Variable	M (SD)	n
Mother		18
Father/Stepfather		8
Husband		4
Grandmother		1
Son		1
Age of Care Recipient	79.56 (11.68)	
Care Recipient Age Groups		
50-59		1
60-69		5
70-79		9
80-89		9
90-99		7
100+		1
Caregiver Hours spent helping Care Recipient (weekly average) [a]		
1-10 hours		9
11-20 hours		4
Caregiver Hours spent helping Care Recipient (weekly average) [a]		
21-30 hours		4
31-40 hours		1
41- 50 hours		1
51+ hours		10

Variable	M (SD)	n
Care Recipient Location		
Care Recipient(s) Live(s) with Caregiver		20
< 2 Hours from Caregiver		6
Different State		2
Different Country		1

[a] N = 29

Of the 29 caregivers, three started caregiving during the pandemic. Four other
caregivers experienced a significant increase in their caregiving responsibilities during
the pandemic, as their care recipient either came to live with them, they moved in with
the care recipient, or the care recipient moved closer than they had been living
previously.

Themes and Subthemes

Caregiver Burden

Caregiver burden refers to the challenges that arise from caregiving and the
negative impact that these challenges have on the caregiver. Caregiver burden was
expressed emotionally, physically, financially, and workwise by the caregivers in the
study.

Emotional Burden. Of the four types of burden (emotional, physical, financial,
and work) described in this dissertation, emotional burden was expressed the most

frequently. Caregivers described a variety of emotional concerns and stressors they have been facing during the pandemic that affected their wellbeing, as well as factors that protected them from burden.

   Expectation and Obligation. Expectation and obligation to be a caregiver caused emotional burden. Caregivers spoke of three primary identity-based factors that fed into the expectation and obligation that they would be the caregiver: gender, familial role, and culture.

   Given that all the participants were women, gender inequality in the caregiving sphere was a common topic of discussion. Though there was not often a clear connection between gender and caregiver burden specific to the pandemic, it was apparent that, in most caregiving scenarios, women were expected to be the primary caregivers for their family members. Thus, women were put at greater risk of encountering caregiver burden because they were often assumed to be the default caregivers for their loved ones. Nineteen caregivers mentioned how their gender played into the expectation that they would be the caregiver for their family members.

> *"I would say probably like the most obvious factor would be my gender. It was just assumed that I was the one who would take care of my mom…In the beginning, my brother was really not helping very much."*

> *"I think that's where being a woman makes it...somehow you are the primary caregiver."*

"My dad came from a generation and a type of family origin where boys were a little more elevated than girls…he is a little bit - if not a lot – entitlement-minded... And so in our growing up years, there was still this kind of mindset of we [as daughters] have to take care of him."

"I think it's just the assumed role of daughters."

"I feel regardless of the situation, I need to be there as much as I can, given even the long distance. And it could be because I'm a daughter."

A caregiver who had been living with and taking care of her father for many years stated her frustration with how caregivers were being treated during the pandemic because most are women.

"These women that had to transition out of the workforce because of the pandemic, and it's happening, and we're not talking about it. I've seen a couple articles, but this should be on the news every day. If it was men...it would be! I hate to say that, but because it's women and ...we just keep doing it. You get up every morning and you put the burden on your shoulders, and you figure it out, and you get it done and women do it. And you know, but at what cost to us?"

Not all caregivers shared the same sentiments about undue caregiver burden being put upon women; some caregivers expressed a belief that caring comes more naturally and effortlessly for women so it is logical that women are the caregivers, despite the burden this may cause.

"I think being a woman also plays a part in caregiving...I don't like to generalize. But typically, women are better caregivers. They're more compassionate, more empathetic. Maybe a little bit more observant…My brothers, no."

"Being a mother…I think being a female, just enables, empowers care, caregiving activities, certainly more than a male would."

Nine caregivers discussed how their longstanding familial role, outside of their gender, played into expectations that they would be a caregiver. Only children felt as though it was their sole duty to care for their parents. For caregivers with siblings, they identified that they were the sibling in their families who were often "in charge" or took "the lead" in family matters.

"We…have a small family in general, many of [my mother's] close friends live far away... She raised me as a single mom, I'm an only child, I'm the only one who's sort of close enough to her to take on the intensive caregiving stuff."

"Because I am an only child, my mother's only child, I see this as my, I am the primary person who has the responsibility for taking care of my mother."

"It was just that family role that had…been part of who I was, for the longest time…the person who fixes everything and makes everything right and takes care of everybody."

"I've always kind of been like this…make everybody happy and have everything

happen."

Five caregivers were immigrants to the United States. An additional three caregivers were born in the United States but were not from white, western European cultural backgrounds. For all these caregivers, their cultural backgrounds often fed into the expectation to provide care.

"Culturally…Indians are known to take care of their elders."

"I think culturally, I think most Hispanic families are supposed to take care

of…their parents."

"The Japanese culture is one that you take care of your family. You take care of

your elders." …I guess I've learned that over all of my life on how you treat the

elders and your parents, and that plays a major role and how I care-give

because that's what I'm supposed to do."

Another caregiver originally from Pakistan said that her "culture" most shapes her caregiving experiences, as, "it's a caring culture. It's a hands-on culture…It would have been normal for my mom to be with me. I'm the oldest… So that's why she would be with me." An African American caregiver said how, when she grew up, "there were several multigenerational homes in my community" and she attributed this occurrence to cultural norms, which normalized her mother moving in with her so she could care for her.

One caregiver who immigrated to the United States from Russia two decades ago brought her mother to the United States from Russia three and a half years ago so she could care for her. She spoke about how her cultural mindset had pervaded her sense of obligation and how she expected to provide care without any public help.

"I came from the country where you do not trust anybody. I mean, government and officials… they all have their own agenda. And you do not expect them…to take care of you."

Worry and Concern. Worry and concern were two prevailing emotions for caregivers in this study and referred to caregivers' present worries and concerns about day-to-day life as a caregiver during the pandemic. Six caregivers expressed concern about the coronavirus and either personally contracting it or their care recipient getting it. Other worries centered around how to keep care recipients safe. Structural barriers, such as the inability to be with care recipients while they were hospitalized at various points during the pandemic, also weighed heavily on two caregivers. For distance caregivers, who were not the primary caregivers for care recipients, they worried about how those physically closest to care recipients were keeping them safe and protecting them.

"The whole cautiousness of the pandemic is what has made it so much harder. I've been hyper cautious because I'm trying to protect [my father] and myself."

"When COVID came along, my brother and I were feeling very worried about having different people come into her household with the virus and didn't want Mom to have any exposure or as little exposure as possible."

"I was really stressed for a long time...worried about it; was I going to bring this virus to my mom? Especially because I have two teenagers in the house. And I felt like, you know, we really can't control our exposure how I'd like to control it."

"On April 1st, right in the beginning of the pandemic, my mom ended up having to have emergency abdominal surgery. And I was not there. And that was really scary."

"Just being worried about from a distance…like the brother who's not very helpful; he's not only not helpful, like with caregiving tasks, he's also more of a detriment because he is out in these rental properties. He actually has COVID right now. He's not careful. He's one of those people who doesn't believe in masks...So that's the thing, even though he's not doing caregiving, I know I always have to ask, when [my father] says something about my brother, I go, 'you didn't see him, did you? He didn't come over, did he?' And now he's got COVID - 'don't let him in!'"

"Inclusive of all the worry we have about the country and more vulnerable people generally…I can't get in touch with anyone who's going to make me feel better about this for my mom and that was really hard. So that's a way I guess that the caregiving has, like responsibilities have changed for me is that like, I

felt it had to be running like interference a little bit on like, 'what are the plans

you're putting in place?' Becoming a sort of amateur disease control specialist,

reading everything from public health departments trying to triangulate what the

right best practices were, and trying to communicate those back to the facility

while being respectful, but they were also under a lot of pressure and trying not

to get in their way. Distance caregiving is definitely a factor also that I'll call

out…I'm doing all of this from very far away. I'm in Seattle, she's in Phoenix, so I

couldn't just go down and talk to someone in person. I was reliant on the email

messages they were sending, or who I could get on the phone. So... that was

hard."

Only one caregiver reported that she and her care recipient had contracted

coronavirus. This caregiver and her mother were the only African American individuals

in the study. The caregiver described the worry and fear that she felt when her mother fell

ill, saying,

"*[My mother] tested positive for COVID. We were of course scared to death….*

We were scared to death. What the hell? …My best friend's mother who lived

down the street from my mother had already died from COVID…. I was, of

course, very upset. She stayed in the hospital for five days."

This caregiver also explained that she lived in a community that was

predominantly Black "that was definitely impacted by COVID," with multiple people

that she knew having experienced discrimination in medical treatment. She was also the

only caregiver who mentioned anyone she knew dying from coronavirus. However, she

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did not feel that her mother had been subject to any discrimination or inferior care due to her race, though she mentioned that they were some of the only Black people in the facility where they got their coronavirus vaccines.

"We…were able to get the first COVID vaccine. I had some hunting around for it, but I got lucky and got her an appointment. And they did me too. But what I noticed when I went there, there weren't a lot of people there that looked like us. So that was kind of interesting."

Anxiety about the Future. Anxiety about the future referred to the anxiety that caregivers endorsed about future events rather than what was presently happening in their lives. Ten caregivers expressed anxiety about the future of care for their loved one, especially given how rampant coronavirus infections had been in nursing and care facilities; when the pandemic would end; and what caregiving will be like when the pandemic is over.

"I'm going to retire pretty soon. I want to enjoy my life. I want to travel…Am I going to be able to travel? Where am I going to put my mother? I don't know."

"What my concern is, when I go to work, I would love to have an adult daycare program. But of course, I haven't even called because I don't know if they're doing it yet until everybody gets vaccinated…Maybe there'll be a little bit more maybe to do if I have to go back to the office because I need to get her up earlier, get her dressed, maybe I need to make an adjustment in the caregiving because I may not want it. I think she could be here, maybe, till I get home, but I'd have to

come straight home. You understand what I'm saying? So, I think when I go back into the office, there will be a bit of adjustment."

"It's really hard to think about… and then you think about nursing homes, and now you're afraid of nursing homes…What about if another pandemic hits? The next one that she's not vaccinated for? And I've been so grateful that she's been here this whole time because she doesn't know that there's one going on half the time. So if she were in a nursing home, she wouldn't either, they'd just be all maskless."

"I don't know when this is going to end…Is it going to get worse? Is it gonna get better? Is it going to get worse and better? Is this going to be six months? Six years? Two weeks? I think that part's emotionally hard because I don't know what this looks like."

Isolation. Eight caregivers described feelings of isolation and loneliness, expressing the difficulties inherent in having to limit their own social contacts and inability to do activities outside of the home. Many conveyed a palpable sense of loss of social connection, as well as the loss of outlets for leisure and doing enjoyable activities both alone and with care recipients.

"We used to play cards with a card group once a month, and maybe go out to dinner with friends or something. We haven't done that at all since last March."

"What's made it tough for me is that it's been very isolating. Very isolating…I get

up, I go to work. Stop work. I take care of my mother."

Though the focus of each interview was on the caregiver, many caregivers also mentioned how the pandemic had affected care recipients, specifically from an isolation standpoint, which had indirect effects on caregivers and caused them vicarious stress. Nine caregivers expressed that the pandemic had taken a toll on the mental health of care recipients due to the isolation.

"The solitude has been overwhelming for [my parents]."

"We're not going out. So, I gotta say, for him, I'm assuming his life is lonelier."

Guilt. Feelings of guilt came up for eight caregivers, sometimes as a reaction to knowing care recipients felt isolated and did not have other distractions and activities. For caregivers who provided daily care, there were feelings of guilt surrounding having to work and not being able to provide more attention to the care recipient. For distance caregivers, there was guilt that they could not provide more care or be there in person more for their care recipients.

"Sometimes I feel really sad because I do have such a demanding job that I feel

like I don't always give him the attention that he deserves."

"So many people I know whose parents are in country A and they're in country

B…We all have this common feeling of anxiety and guilt, that we are not where

we are needed."

Devalued and overlooked. Seven caregivers described feelings of being devalued and overlooked in the important societal role they play, particularly during the pandemic. There was a sentiment that informal caregivers felt that they were not valued during the pandemic as essential parts of the healthcare system and did not have the same advantage as other healthcare workers, such as early eligibility for the coronavirus vaccine. Three caregivers mentioned this explicitly. Two caregivers described how other family members and loved ones had failed to check in on them and see how they were doing or offer to help.

"I didn't technically qualify as [my mother's] caregiver, [home health aide's name] can get it…because she's a home health aide. But they're not considering caregivers like me as caregivers, which kind of stinks."

"Neither one of my siblings has picked up the phone and said, 'Hey, how are you doing? How are you managing? Does Dad need anything? Do you need anything?' That has not happened. And that's been very hard."

"It would have been nice if someone asked how I was doing."

Caregivers' ages also caused a caregiver to feel overlooked or devalued. One caregiver in her early 30s discussed how she was "on the younger side" for being a caregiver and some people erroneously assumed that it was not "that bad" and was easier for her because she was unmarried, had "energy," and did not have kids. Alternatively, another caregiver in her 60s, remarked how her older age helped her feel more included

and seen because she could participate in the same activities as her husband for whom she provided care.

> *"My age is helpful in some ways. I think being old enough- being over 60 I should say- because we can take advantage of senior center programming."*

Overwhelmed. Fifteen caregivers described feeling overwhelmed in some way by caregiving during the pandemic. Due to the nature of the pandemic and the dangers that arise from having many in-person social interactions, many caregivers increased the amount of care that they had been providing, as well as took on new caregiving responsibilities. Some caregivers described a decrease in professional care from outside professional providers, which meant that familial caregivers had to increase their duties. Others talked about how other friends and family who had helped with caregiving prior to the pandemic were no longer helping to minimize the risk of spreading the coronavirus. Due to the increase in caregiving responsibilities and the reality that many interviewed caregivers were the sole caregivers for their loved ones during the pandemic, caregivers frequently found themselves with much less personal time. Caregivers did not get a reprieve from caregiving to rest and recharge, which weighed heavily on them and impacted their mental health.

> *"Quite often, I feel like the weight of the whole household is on me."*

> *"A lot of the crying-to-my-therapist-type conversations. I would love to delegate things. But I can't delegate as much as I would like to."*

"In the last year, I've gotten nuts. I've literally been in my house since February...
it started in February because my last business trip was in February, and then my
company shut us down March 15 or whatever it was. It's been a year and I've had
no break."

One caregiver talked about how the intense privacy of American culture made it
difficult for her to cope with feeling overwhelmed with caregiving.:

"One thing I found with this country...it's like a lot of things are very private. We
don't share information...whereas back home in India, everything is out in the
open. I mean, even how much money you make is out in the open...So there's a lot
of things about privacy that you know, positive and negative. This is one of them
where you don't necessarily end up talking about your caregiving stress."

Some caregivers, however, remarked on how facets of their identities, such as
their race, having a high level of education, and knowledge derived from their careers
were protective factors that kept them from feeling overwhelmed with the intricacies of
caregiving.

"My level of education definitely puts me in a better spot."

"I am not gonna lie and say, you know, I'm not resourceful. I've been a social
worker for 30 or so years. So, I know how to find stuff."

One caregiver who worked in health care remarked how her knowledge of health
care systems and "health literacy" mitigated "that complexity of navigating the
[healthcare] system" for her parents. Another caregiver said that her identity as a

"middle-class white person…who's very well educated" had "helped" her in her caregiving duties because she knew "how to tap into networks."

Physical Burden. Implications to physical burden were mentioned less frequently than emotional burden; only four caregivers mentioned any allusion to the physical impacts that burden has on them. When it was mentioned, physical burden was tied to experiences of emotional burden, such as stress and anxiety.

"I believe the caregiver stress caused me to have this two-week mystery illness. And then once the mystery illness went away, I started having all these joint pains, and the doctor was saying, because I had a prolonged fever, possibly the virus got into my joints, and all this joint and nerve pain. And now I'm going to a chiropractor to help with that."

"*My go-to for when I have anxiety… is eating. Naturally, I've gained some weight over this whole time. I've always been heavy but gained some weight over this time."*

Exhaustion. Caregivers expressed both emotional and physical manifestations of exhaustion. One caregiver reiterated the struggle she had with the constancy of caregiving and relayed it as "very mentally difficult. And physically tiring." Another caregiver, who provided care for her older mother, disabled 23-year-old daughter, and husband who cannot drive, stated, "I'm just so tired…I feel that I'm so drained; I have no emotional strength anymore…I sometimes just want to sleep."

Financial Burden. During the interviews, allusions to financial burden were evident. Three caregivers decreased their working hours to provide care and two caregivers retired earlier than expected to safely provide care for their mothers. These reductions in work decreased caregivers' incomes. Even for those who maintained the same number of working hours, caregiving during the pandemic had impacts on their career progression.

> *"I'm making money, I'm contributing towards a retirement plan for my own future, but I'm not making as much as I could have. Because I have all these caregiver responsibilities."*

A caregiver who started caring for her mother who had cancer during the pandemic took time off work to care because no one else was available to help her mother, which stifled her ability to earn more through promotions.

> *"I was moving up. I had just gotten a promotion in March; I was looking to get another promotion in October. I was hoping to continue that moving forward. Now, because I was gone for a month…I have to basically start all over."*

As one caregiver put it, "every part of caregiving has to do with money in some way." For three caregivers, moving a care recipient to a skilled nursing facility was not a consideration due to cost, which meant that caregivers faced the prospect of having considerable caregiving duties well into the future. Other caregivers were having to reconsider their finances and jobs.

> *"We couldn't afford [a nursing home], and two, they didn't set themselves up for…any of that."*

"Cause my mom's on a limited budget, and there's not enough money to even like.... I have looked for nursing homes, I've looked for in-home care, but everything would be out of pocket. So, the only thing I've got going for me at this point which I have to go for is Medicaid. I have no other choice... because assisted living here in North Carolina- it's $4,000-6,000 a month."

"I really would like to continue to work until the house is paid off, which will be another couple years. But I've been thinking…that I probably would have to give up my job and maybe find something else…We might have to sell the house and take early Social Security…since I do feel like he is going to require more care."

One caregiver owned a small business and worked for herself. She had decreased her working hours due to having to provide more care and because her customer base dwindled during the pandemic. She was the only caregiver in the study who received compensation for caregiving through a state-run program; this caregiver reported her income (inclusive of this compensation) in the lowest income bracket, less than $25,000. She stated, "Yeah, nursing facilities, or assisted living facilities are just way too expensive. We couldn't afford that for her."

Three caregivers talked about the dilemmas of care recipients being middle-income, which meant that care recipients did not qualify for subsidized care services under Medicaid, but most private-pay professional care services were financially out of reach.

"My mother makes just enough to not qualify for anything. Like she's just over the income threshold."

"We actually had somebody that came in for four hours twice a week, and she would help me with the house, vacuuming or whatever. But we couldn't afford it. We couldn't sustain the amount what it cost. And I think it isn't that caregivers don't want the help. But you've got to have the money to pay for that help. And that's also a difficult position. In our society, you either have to be wealthy or you have to be destitute. It's the in-between that's the problem. If you're destitute, you can get help. If you're very wealthy, you can pay for whatever you need. But boy, it's people that are in the middle that really struggle the worst."

Two immigrant caregivers mentioned the challenges they faced due to barriers to obtaining publicly subsidized services and insurance like Medicare and Medicaid.

"The whole other thing in the U.S., as contrasted to Canada or UK, we cannot immigrate our parents here…But because of health insurance, what the hell are you going to do? That's a whole 'nother set of considerations."

"According to the immigration laws, because I brought my mother - it's my will to bring her- I can't ask for any government assistance for five years…five years, I can't claim anything."

Conversely, five caregivers acknowledged the privileged position they were in due to their own or their care recipient's socioeconomic status, which prevented them from experiencing financial burden and faced less difficulty in accessing medical care.

"My parents had good pensions, they had good insurance. My mom doesn't pay much out of pocket at all other than for her insulin, so I definitely know that…has been very helpful for me."

"Because of our socioeconomic status and my mother's socioeconomic status, I think she has better access. That makes a difference. Money makes a difference."

"And the other thing that's made [the pandemic better for me] is the fact that I can afford a home health aide. Not everybody's in that situation. It's very expensive…I think I'm paying 28 bucks an hour. Yeah, it's a lot."

"For the most part, they've been self-sufficient. They weren't extravagant individuals. I support them financially in other ways…I own their home, I pay their taxes, their insurance, if something breaks down in the house. They're on Medicare and supplemental insurance. My dad did qualify for state Medicaid after his hospitalization, [which] was ridiculous…they were never of well-means. They managed to raise children who became really well educated and fortunate enough to have good jobs."

"I am incredibly lucky to have chosen the career that I chose in terms of prioritizing something that pays young people really well relative to some other career paths. At a time when I unexpectedly needed more money than I ever thought that I would, in my 20s. That feels like something I certainly did not do intentionally. But that has become more useful than I ever could have imagined. In different ways than I imagined. I think when I started working in technology, I might have said, 'maybe I can get a mortgage sooner than I thought'… and I certainly was able to pay off student loans sooner than I thought. Never, though, was I thinking, maybe I can allocate 1000s of dollars a month to take care of my mom sooner than I thought."

Work Burden. The workplace and the home newly merged for 19 caregivers during the pandemic as they transitioned to working from home, which meant that working and caregiving roles often collided with one another in a physical space-related sense. Many caregivers discussed the difficulty and mental strain involved in caregiving and working simultaneously. Family-work conflict, wherein caregiving interfered more with work than vice-versa, was particularly common. Three caregivers described how care recipients would interrupt workflow or concentration that the caregiver required while working at home.

"[My husband] would always stop by my office and if he needed something, or he had a question, he didn't hesitate to come in."

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"Sometimes I have to…close my door because he'll come in and ask a question, which is fine, but it's interrupting."

"Yesterday…I had a class with students starting at 5pm. And exactly at two minutes to five, she started calling out my name…So I had to type in the chat, 'I'll be right back. Please start. I'll be right back.' And I keep doing that to people. I'm afraid, if I don't go, if she falls, that's an even bigger risk…more of my time…away from what I'm trying to do."

Caregivers found that the increase in caregiving responsibilities precluded them from being able to work more or they had to sacrifice necessary personal care, such as sleep, to manage both. One caregiver who cared for her grandmother and young children talked about how imminent changes to her job "will mean that I will be working night hours that I was not before so I will lose sleep. Literally, I will lose sleep as result of the change. But such is life until…we're fully immunized." Others described the difficulty they had in focusing on work due to heightened concerns about care recipients during the pandemic.

"At the beginning, I poured in a lot of time [to work]. During the pandemic, however, a lot of it had to do with my mental state…I kind of pulled back on the business a little bit, because I was so worried about taking care of my mom and my sister."

"It's sort of, it's probably more of a mental thing...it's just, my ear is always listening to see, is he okay? what's he doing? It's like a constant back of my mind worry...It's sort of like a constant mental program that's running in the background. So, it's not like I can be 100% focused on work."

Another caregiver ended up retiring from her job at a university because of the difficulties she had in managing both an arduous job and caring for her mother full-time. Prior to the pandemic, she lived in a different state than her mother and only provided care on the weekends, but the pandemic forced her to co-reside with her mother for ease and safety purposes, which she found challenging due to her working hours, which also increased during the pandemic. This caregiver presented her decision to retire as a way to "take better care of" both her mother and herself.

Work-family conflict, wherein work interfered with caregiving, did come up as well but less often – only two caregivers mentioned this explicitly. A caregiver who provided care for three family members described how she could not endure the "demands, which [administrators at my workplace] put on us" much longer and she was going to retire "because I have a double load or maybe triple load at home." A caregiver, who had been covering for colleagues who left her company, emphasized "the overall overwhelming part of having a demanding job. And not feeling like I've got the time and attention [for my husband]."

The Role of Workplace Policy

Workplace policy has the potential to either alleviate or exacerbate caregiver burden. Caregivers were asked to describe how their employers had supported them

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during the pandemic, with examples of policies provided for prompting. Three categories of policies emerged: those that addressed flexibility in working and caregiving, those that addressed leave time from work, and those that addressed resources available through the workplace for caregivers. Access to policy depended on a variety of factors, such as how many hours caregivers worked and the type of job that they had.

Flexibility. Policies that addressed flexibility enabled caregivers to choose their own work location and work schedule.

Work from Home. For the sake of public health, working from home became a mandatory policy for many workers at the start of the pandemic in March 2020. Given this ubiquity, caregivers were specifically asked if they transitioned to working from home when the pandemic began. Only one caregiver who worked in a grocery store had a job she was unable to perform at home at any point during the pandemic given the nature of the work. Another caregiver said that the software that she needs for work was only on a computer at the office, so she continued to go into the office throughout the pandemic but emphasized that there were only three other colleagues in the office at any one time while she worked. Ten caregivers worked at home prior to the pandemic and continued to work at home, and the remaining 17 caregivers started working at home during the pandemic, indicating a change in workplace policy for them. Of these 17 caregivers who started working at home, six had returned to work in person in the office in some capacity, either full-time or a few days a week, and one had retired when interviews took place in February to April 2021.

Caregivers who switched to working from home cited the ability to work from home and be home with their care recipient more often as a welcome change that eased both emotional and work burden for them. Working from home meant that commutes were eliminated, which allowed "more hours for caregiving during that time." Caregivers appreciated the convenience of being able to get errands and other tasks done during the workday. The flexibility inherent in working from home addressed caregivers' emotional burden of feeling overwhelmed by all they had to do and gave them a better ability to multitask. Caregivers went so far as to say that, because working from home was now an option, the pandemic had made managing work and caregiving "easier."

> *"I got set up so that I was remoting into work. I only went in one day a week, and I work in [a city far from my house]. So quite a drive. So, I like working at home."*

> *"I've been at home for the pandemic, which has been really nice, because then it allows me some flexibility to like, you know, make an appointment and take my dog to the doctor, I can do emails…I think that's nice just to have a little bit more freedom and flexibility."*

> *"I can reinforce that working from home during the pandemic has been a godsend, allowing flexibility to keep being sure I do a good job with my position and am available to supervise what might be going on for housing, care, food, etc."*

"It made it a little easier for me because it's almost like things are a little bit more flexible working from home. It's just kind of the nature of the situation. So, it made it a little bit easier for me if I had to run [to my father's house] for something. If it was really urgent, maybe I could run there…take a long lunch hour, and come back… I wasn't leaving the office so much it would be you know, just working from home made it a little easier."

"It has been a little easier because my employer has been good about it and I can work from home. There's been a couple instances where I've had to take him to the ER, and they're like, 'No, it's okay. You can work from home.' It's a thing now versus before... you take a day of vacation or whatever. Now, it's, 'well, you know, what to do. You know how to get online.' It's acceptable to work from home and before, it was not a thing."

However, working from home was not positive for every caregiver. For some, working from home increased emotional burden. One caregiver described what it was like trying to balance work, personal time, and caregiving for her mother while working from home and found it challenging, saying, "it's like, [my mother] knows I'm here. So, I don't get as much downtime with COVID." Two caregivers who had previously been working from home during the pandemic were relieved to be able to return to the workplace parttime because working from home was not conducive to productivity for them and exacerbated their work and emotional burden.

"For my own sanity, I jumped through so many hoops to get back on campus for two days a week…between a husband with ADD and a child, it was just…I can't really get much done at home."

"From mid-March to early August, I worked solely from home. And that was awful. I know some people thrive…With my dad in the house and the noise he makes…And plus, I had moved my computer down to my partially finished basement when he moved in…So it wasn't the most pleasing environment to be in."

The one caregiver whose job at a grocery store did not allow her to work from home expressed gratitude for being able to go to work outside of the home, helping her better manage her emotional burden, stating "my work has not stopped at the grocery store. And so, thank God, I get to go to work." The caregiver who continued to go into her office job reiterated this sentiment, emphasizing how going into the office helped her feel less isolated and manage the emotional burden of caregiving.:

"I need to get out of the house. My three days a week [in the office] kind of give me a sense of normalcy. And because my husband is so physically disabled, and mentally too, but so physically disabled, it's, I have to do everything... Help him get dressed, I have to help him get undressed. I have to feed him…Everything. So those three days a week, that's the reason I actually work...is to just talk to somebody else besides him!"

In one unique case among the interviewed caregivers, a caregiver who had been fully remote at work early in the pandemic was required to return to work in-person

before she felt comfortable, which no other caregiver reported. This mandate from her employer added to her emotional burden by increasing her worry and concern about contracting the coronavirus and spreading it to her family members, as well as causing her to feel devalued. All of this contributed to the negative opinion that she had of her employer and worsened her emotional burden.:

> *"When I asked them to give me an opportunity to teach from home again, like we did spring and summer and nobody complained…They said no, only those who have critical diseases like diabetes…there is a listing of certain approved diseases...when you required by federal law to give special accommodation and because, my situation, I'm pretty healthy. And because it's my family, I'm healthy, because I'm one who brings in COVID if it's happened, so I applied officially applied and I was rejected. I felt really betrayed…They tell you how they... value us and blah, blah."*

Schedule Flexibility. Beyond the flexibility of being able to work from home, flexibility in scheduling and when a caregiver worked were highly prized during the pandemic and addressed work burden that caregivers experienced. Flexibility in scheduling tapped into improved work-life balance for many. Seventeen caregivers endorsed having flexibility in their schedules, including the three caregivers who were self-employed and set their own schedules. Caregivers discussed being able to spend more time caregiving during the week, such as taking care recipients to doctors' appointments, and the ability to make up work hours at other times when they did not have caregiving responsibilities. Flexibility in scheduling meant that caregivers did not

have to miss work when their loved ones had health crises, as well as enabled caregivers to maintain the same number of working hours in the face of increased caregiving responsibilities during the pandemic.

"I'm very fortunate. I have an ultra-flexible job in my hours. Because I am very independent, and I don't have to make certain meetings… most people work around me. I marked my calendar off when I need to be out and that kind of thing. So, I'm very lucky."

"I think the main thing that I need, which I'm getting, is flexibility…The firm times that I have to be someplace are not very frequent."

"One thing that that they do offer…they're very flextime friendly. My dad has a doctor's appointment…tomorrow morning. I'm going to get up and start work at seven and work a few hours and then take him to his appointment, get him home, and then I can get back to work. And if I need to work a longer day. Or if I don't get my eight hours in today or tomorrow, then I could potentially work through my lunch on Friday and make up that time."

"I've got a great deal of flexibility. During my mom's surgery, I did not take time off. Although I was down there the whole time, I was able to work around it."

Flexibility was so highly prized that one caregiver said that she could make more money working in another job but did not want to give up the flexibility that she had,

saying, "I could easily make $10 to $15,000 more elsewhere. But I don't want to…if I was getting more money, they'd want me at their beck and call. Here, it's less money, but it's more flexibility. Better work-life balance." Another caregiver said that her flexible work schedule enabled her husband to remain at home for care rather than having to go to a facility; she described it as "the perfect situation with being flexible in my job, and still able to keep him at home. That's our goal."

Flexibility policies were not perfect at all companies. Some caregivers pointed out the inconsistency in flexibility policies between departments and among those with different job roles.

> *"They're not consistent with some of their policies. Prior to the current president, we allegedly had flex time, but it was never in my department, but...IT was able to come in at all sorts of flexible times."*

Parttime Status. The ability to work parttime speaks to flexibility that caregivers have in the amount of work that they do on a weekly basis. Working fewer hours can reduce work burden for caregivers. Five caregivers worked 30 hours or fewer at the time of interview. Three of these five caregivers worked parttime because caregiving occupied so much of their time, indicating that caregiving caused work burden because it interfered with their ability to work fulltime. One caregiver did not specify why she worked parttime hours; the fifth caregiver was a self-employed photographer who experienced a decrease in business due to the pandemic.

One caregiver who worked 20 hours a week for a nonprofit said, "There's no way I could do a full-time job right now with my caregiving responsibilities. It's possible, I

suppose if it weren't for COVID? I mean, certainly people do. But I can't imagine that happening in my situation, to be able to work full time," alluding to the additional work and emotional burden she would face if she tried to work more. However, she described the conundrum she faced working parttime and not getting benefits as a parttime employee, which caused financial burden for her.

> *"If it were a big corporation, that would be different, but a smallerish nonprofit, I just don't expect that they would have resources to…pay me if I'm not there…I don't get vacation days, those kinds of things where if I were even working at Walmart parttime, there's benefits."*

For other caregivers, the ability to work parttime was not clear-cut. Three caregivers currently working fulltime affirmed that they could work parttime in their current roles. However, four other caregivers were unsure if they could decrease their working hours; they said that this was something that they "probably could" do. Three caregivers said that if they wanted to work parttime at their companies, they would have to switch job roles within their company to jobs that could be done on a parttime basis since their current jobs could not be done parttime. One caregiver said that her employer did not "offer many parttime positions" so the option to switch to parttime work was not available to her. Even for caregivers who had parttime work available as an option, companies still may not support parttime work in execution with the workloads that they assign and the expectations that they have, which caregivers then internalize as the amount of work they must do to stay employed.

"It would be amazing as if they say, you know what, you can take this make this a parttime job because you have this caregiving duty. But truly parttime, not like, three days, but do the work of five days in three days. That's what happens, especially with moms, I suppose. And maybe it's our mistake as well, that we think we need to do five days' work in three days. Whether they pay us or not. I think a lot of it is self-inflicted, but the fact that it's not available, you have to set up proceedings, you're afraid of job security these days."

A few caregivers discussed what would happen if they dropped from fulltime work status to parttime and the financial burden this would cause. Two caregivers who endorsed that they could work parttime in their current jobs said that they might lose benefits, like health insurance and life insurance, if they worked fewer hours. Others simply "couldn't afford to do it," which was particularly salient for those who were single or the sole income-earners in their households, indicating that relationship status and family dynamics were important considerations for them.

Leave Policies. There are multiple types of leave from work that an employer can provide for caregivers. Three of the most common types are: paid time off, sick leave, and family leave (actiPLANS, 2020). Depending on whether the leave is paid or not, leave time could address any or all four types of burden.

Family Medical Leave Act (FMLA). The only federally mandated leave available for caregiving, FMLA, provides 12-weeks of job-guaranteed unpaid leave to workers to care for themselves or a family member and applies to companies with 50 or more employees. Given its unpaid nature, FMLA does not address financial burden, but is

aimed at cutting down on work burden by ensuring that an individual retains their job while fulfilling caregiving duties. FMLA also has the potential to reduce emotional and physical burden by enabling the caregiver to take the time they need off work to care for themselves or others without fear of losing their job. Ten caregivers explicitly mentioned FMLA as a type of leave that they could take to provide care for their loved ones.

Two caregivers reported that they worked for companies that were too small to qualify for FMLA. One of these caregivers said that her employer had "allowed other people to take leaves of absence," though she was unsure if she would have the same option given her job role. The three self-employed caregivers did not qualify for FMLA given that they were their companies' only employees.

Paid Time Off (PTO). PTO is job-protected paid time off than an employee can use at their own discretion. This is typically synonymous with "vacation time." This leave can be taken for any reason, and thus could be used to alleviate emotional, physical, financial, or work burden.

Four caregivers lauded the PTO policies at their companies, which eased financial and emotional burden. Two of these caregivers had unlimited PTO; two others who worked for universities cited the "generous" PTO that they had, which left positive impressions on them. One caregiver discussed the unique scenario she had at her job wherein other employees could "donate" their PTO to her for caregiving purposes.

Three caregivers reported that their PTO was merged with either sick leave or leave they could take to provide care for their loved ones. For these caregivers, there was no separation between time that caregivers could take off for their own leisure and time

they take off to care for others; it was all considered to be the same pool of general "PTO." This has implications for emotional, financial, and physical burden, because caregivers may expend the time they reserve for vacation to provide care, which eliminates their ability to take paid time off work to recharge and take care of themselves. Differences in how parents and caregivers of older adults were treated and what kind of leave they had to take to provide care came up during discussions about PTO, which was a further indication of how caregivers of older adults are often overlooked and devalued.

> *"It's all vacation time. I don't know...I guess it's kind of frustrating because I think people, if their children are sick, or if something happens with their kids, it's acceptable that they take sick time... And then with my dad, it's like, he kind of is my child. I care for him in the same way. Yeah, but it's mostly vacation time I have to take."*

Sick Leave. Sick leave has the potential to address physical, financial, and work burden, depending on the parameters of the sick leave. However, of the types of leave available for caregivers, sick leave was mentioned the least, with only five caregivers discussing it. One caregiver said that her company recently "mandated" sick time, which started January 1st, 2021. Two other caregivers talked about the abundance of sick time they had: "100 and something days' worth of sick time," while another had "unlimited sick time." However, another caregiver mentioned that the only paid time she had off work to provide intermittent care for her father was sick leave, which reduced the amount of sick time she had available for herself, thereby putting her at risk for greater physical burden if she or her father were to become sick.

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Pandemic-Specific Sick Leave. Three caregivers referenced the Families First Coronavirus Response Act (FFCRA) policy that was enacted in March 2020 and expanded paid sick leave for workers. This policy was intended to relieve financial and physical burden by ensuring up to 80 hours of paid sick leave for all workers, thereby encouraging sick employees, as well as those caring for sick loved ones, to stay home from work to cut down on the transmission of the coronavirus. One caregiver who eventually left the workforce said, "Initially, I used the two weeks COVID family relief," before she left her job completely, which enabled her to have two extra weeks of pay that she likely would not have otherwise had before she left her job. Another caregiver was not aware that this was a federal measure and attributed this additional sick leave time to her positive opinion of their employer, indicating her overall approval of it.:

> *"I work for a pretty good company, and they extended our sick leave. So specifically, if somebody's sick with COVID, or they are exposed, they wanted to encourage somebody to stay home and be honest about the diagnosis and not be afraid to miss work…I appreciate that. Because often…you show up for work, no matter what."*

Paid Family Leave. Paid family leave addresses emotional, financial, and work burden by ensuring that caregivers maintain their income while they are caregiving on a full-time basis. Nine states plus Washington D.C. have passed paid leave laws, with seven of these ten municipalities paying out benefits to employees as of November 2021 (A Better Balance, 2021). Four caregivers lived in areas with these laws enacted. Five caregivers who did not live in states with paid leave laws in effect knew they had access

to paid leave through their workplace. One caregiver said that she had "EI benefits" that she accumulated over time that she could "use to take my dad to doctor appointments or anything to do with that type of situation if it's an emergency."

There were varying perspectives on paid leave laws across caregivers. Some caregivers expressed gratitude for the paid leave that they had and how it kept them from being completely overwhelmed, while others felt that that the paid leave they had could be more expansive.

> *"At the end of November for about a month, I ended up going on full leave. Just because it was just too crazy to do everything…I still got paid full pay during…that time…And the intermittent was paid leave too so I was very supported…I don't know what I would have done if my company hadn't allowed me to take full leave."*

> *"I think it's just a standard 12 weeks, and…I think it's paid, but it's only like a percentage. It's not 100%. So, they do have some sort of… it wasn't great. Let's just put it that way. It wasn't like, 'Oh, you know, what a relief. I'll still get my full salary if I need it!' It was kind of like a portion of my salary only and it was not terrific. That was just like the bare minimum number."*

> *"I think they do six weeks paid. That's what they do. I don't think they do total weeks…. I think it's something that people should know more about. It should be*

more talked about and used so people don't feel guilty or don't work 80 hours a week. Combined, right, caregiving and work and everything."

One caregiver who did not have access to paid family leave, but otherwise spoke highly of her employer, said that the main thing that her employer could do to be more supportive of her would be to "pay…me to take time off to deal with my parents."

Multiple caregivers were unsure if their workplaces had paid leave policies. Additionally, one caregiver who lived in a state with a paid leave law was unfamiliar with the particularities of the law and instead used her vacation time for leave when her mother had a stroke. Another caregiver stated that she did not have access to any paid family leave, though she lives in a state with a paid family leave law and would likely qualify for it based on her employment history. This indicates that paid leave policies are not widely discussed or promoted at many workplaces. One caregiver talked about how she had taken leave in the past for caregiving purposes and had not even considered whether it was paid or not because "sometimes those categories in life, you just do what you gotta do."

Pandemic-Specific Paid Leave. One caregiver had a particularly generous coronavirus-related leave policy implemented in her workplace, termed "COVID pay," which was intended to alleviate both financial and work burden during the first year of the pandemic. "COVID pay" was a form of paid leave that was provided to employees who had additional caregiving responsibilities during the pandemic and were unable to work in the same capacity as they had prior to pandemic. This policy enabled employees to retain their incomes even if they had to decrease their working hours. When this

caregiver was asked to rate how supportive her employer was, she rated it as a 10/10 because "I know my benefit was so above and beyond what other people's situations are, that I can't give them any less." However, she also expressed distress that this benefit would cease to exist soon, adding to her sense of emotional and work burden.

> *"It's anxiety, having to find time to make up these hours that I've had the pleasure of not having to worry about for the last year, and the increased dependency on my spouse to cover some of the roles and responsibilities that I have with both my grandmother and the children."*

Resources. Employers provided resources that are aimed at promoting employee wellbeing. These resources can reduce the emotional burden that caregivers experience from managing work and caregiving roles.

Employee Assistance Programs (EAPs). EAPs are intended to address emotional burden and help caregivers by providing resources, such as counseling and case management, to caregivers who may feel overwhelmed or experiencing negative emotions related to managing work and caregiving simultaneously. Twelve caregivers mentioned EAP benefits that their companies provided them; all of these programs existed prior to the pandemic. Five caregivers had used the EAP resources available to them, with varying results. Two of these caregivers praised their EAPs; another caregiver had not yet used her EAP but said she was going to look into it as place of support and to ease her feelings of isolation in not knowing what to anticipate in caregiving for her son with ALS. The rest of the caregivers with EAPs were indifferent to them or had limited success with the resources provided.

"One thing [my employer] does right is they have this really expansive EAP program. Includes…elder care consults…I called up the EAP and be like, 'there's family drama, I'm now responsible for eldercare.' They hooked me up with somebody who spoke to me for over an hour, giving me the crash course and elder care and weighing the pros and cons of does she stay in New York? Does she come to Massachusetts? And the EAP person was telling me like, you know, 'the elderly person needs to live closest to the primary caregiver. So, get your mom on all the waiting lists in your area, and then move her when you can.' So that was helpful."

"They have tons of webinars with employee assistance, and things to help like manage stress."

"We have an EAP program, which is, as far as EAP programs go, it's what it is. I mean, I'm not overly impressed with it. Um, they do have some…just some resources online."

"I think they're talking more about [caregiving for older adults] these days, but I don't think enough to say people will jump and make use of programs that might be available, like EAP. I've used it once. It seemed like somebody did the research for you, instead of you having to do the research. But that was it. That was the end of it."

Four caregivers said that their EAPs provided resources specific to caring for older adults. However, three other caregivers with EAPs mentioned how their workplace provided resources for employees who had caregiving responsibilities for children but not for caregivers of adults.

"I see a lot of things for people with kids. But that's pretty much it."

One caregiver without an EAP expressed the irony of not having more case management help for caregiving even though her workplace provided those services "in house" for clients." She further stated that her employer was "quite stringent about staff not receiving the work that we do." Finally, four caregivers seemed not to know whether they had an EAP or if their EAP would help with caregiving.

Pandemic-Specific Resources. Two caregivers mentioned financial measures their companies provided during the pandemic that addressed financial burden that caregivers may have had. One reported that her workplace had "employee funds so if any employee is really needing more help, you can apply and get more money." Another workplace that sent all their employees home at the start of the pandemic guaranteed pay for all workers through June 30, 2020, regardless of whether the employee could do their job at home or not.

Some companies also made efforts to alleviate emotional burden of employees during the pandemic through other resources. One caregiver mentioned virtual free meditation and yoga classes for employees that her workplace offered throughout the pandemic, which spoke to efforts to address both emotional and physical burden.

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See Table 3 for the categories of workplace policies and which burdens they
addressed.

Table 3

Workplace Policies and Burdens they Address

Type of Policy	Policy	Burdens Addressed
Flexibility	Work from Home	Emotional Burden Work Burden
	Schedule Flexibility	Work Burden
	Parttime Status	Emotional Burden Work Burden
Leave	FMLA	Emotional Burden Physical Burden Work Burden
	PTO	Emotional Burden Physical Burden Financial Burden Work Burden
	Sick Leave & FFCRA	Physical Burden Financial Burden Work Burden
	Paid Family Leave & Pandemic-Specific Paid Family Leave	Emotional Burden Financial Burden Work Burden
Resources	EAPs	Emotional Burden Financial Burden Work Burden
	Pandemic-Specific Resources	Emotional Burden Financial Burden

Other Workplace Factors

Caregivers did not focus solely on workplace policies when discussing what made their workplaces supportive and impacted caregiver burden. They also mentioned other workplace factors that either eased or exacerbated burden.

Supervisor Support. Though the emphasis in the interviewer questions was on workplace policy and how workplace policy had supported working caregivers, many caregivers mentioned how valuable the support of their direct managers had been in enabling them to manage both caregiving and work responsibilities, thereby, reducing emotional and work burden for them. Eleven caregivers explicitly discussed how supportive their supervisors have been and how critical this support has been to them. During interviews, caregivers were asked to rate their employers on a one to ten scale and those who rated who gave high ratings to their workplaces often attributed these ratings to their managers.

> *"It really comes down to how your boss works with you or works against you."*

> *"What I found is the most important thing in terms of when you're in this caregiver role is your immediate manager…and how your immediate manager supports you…that's been the most helpful part for me."*

> *"From kind of a personal standpoint, my manager was incredibly understanding throughout the process. I was keeping her pretty updated on everything that was happening as it was happening. She was kind of going through everything with me, and which I think helped a lot."*

"[My manager's] been wonderful. He knows [that I'm caregiving] and I hope whoever goes into his shoes, will have that same attitude. If not, then it's gonna have to change in my world, because I can't keep up with doing both and working at night and then taking care of my mother. There's just no way."

"I would say, my direct supervisor, probably 10, because she is so willing and understanding and she has a family of her own."

A caregiver who felt that she was not supported at work in her caregiving duties also emphasized the importance of understanding and empathetic leadership in a company, discussing that there had been leadership changes at her company which had changed the tenor of the workplace and the level of support that she feels, causing her to have concerns about balancing work and caregiving.

"Had it been the prior leadership team that was in place, we'd be having a different conversation, it would have been a no brainer, they would have said not to worry, take your time, because I've seen it done with others who experienced similar, either a loss of family member or really, you know, severe illness with a spouse. I would like to think that they would accommodate me, but I have not tested that, and they don't know about my circumstance."

Workplace Culture. Caregivers discussed the overall culture and ethos of their places of employment and how this factored into caregiver burden and how they viewed their employer and experienced the pandemic as a working caregiver. Supportive workplaces had the ability to ease work burden and enabled caregivers to continue

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providing care while working. Some caregivers had improved perceptions of their employers when they noticed that their employers had responded well to the changes in their lives that occurred due to the pandemic. Other caregivers mentioned that, due to the nature of the work that their workplaces do, they understood caregiving more.

"About my family and my life…I feel like [my employer] would be receptive. If I was like, 'Look, we are really struggling. I can't show up. What can we do?' And they would probably work with me or help me find a position that supported that lifestyle, whatever it is."

"I'm very lucky that I am able to work at a place that understands disability and caregivers…I think that that has made a big difference in my ability to keep working and take care of my husband."

"I feel like they've been amazing and even just in terms of 'Gosh, do you have somebody at your house that is disabled? Or that you're concerned about?'"

"About two, three months into COVID, they started really asking... supervisors asked employees, I think part of that was because we never had a relationship before where they asked about caregiving activities or made those accommodations without the employee coming forward. So, it was part of the company's ethos. Once we were a few months in, and it was obvious that we, the world was different…it became part of the supervisor's responsibility to talk to

their employees about their experience with COVID and how it was impacting or

...they estimated that it would impact their work."

Despite some caregivers endorsing supportive workplaces that helped them provide care while working, other caregivers said they work and provide care despite their employers' lack of recognition for their caregiving duties. Caregivers reported that they "do not feel comfortable sharing" their caregiving responsibilities at work, adding to the emotional burden of feeling isolated in their caregiving. Caregivers described their workplaces as "indifferent," did not feel that they could "safely" request a change from fulltime to parttime work status without putting their job at risk, and felt as though their employers did not care about them. In some instances, employers actively made caregiving more difficult for caregivers, such as in the case of the caregiver who requested to teach class virtually but was instead required to teach class in person during the pandemic.

"But if someone did recognize that this is not a normal situation without the

pandemic, and then you throw the pandemic on top of it, and you have a person

that's working for you and still performing and still delivering, check in with them

and make sure that they're okay."

Awareness of Workplace Policies. The ways that caregivers found out about their workplace policies also spoke to workplace culture and the level of endorsement that companies had for accommodative policies. Caregivers who were enthusiastic about support from their workplaces described the comprehensive communication efforts that their employers displayed to promote helpful policies. Open communication about

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policies and policy changes meant that caregivers did not have to take on the additional

labor of searching for workplace policies, which could further overwhelm them.

"One of the things when they were giving the webinars, they were throughout the

year, and they still are going, there's some, like, how to manage stress during the

pandemic, and all these, you know, different topics. And one of them was on just,

like, policy, making us aware of the resources that we had. One of those things

was paid leave."

"We have an internal…intranet that we use for the company. And I think I just

typed in 'leave' and was able to find quite a bit of information on there. And then

talk with my manager. And then we talked with our HR business partner and were

able to figure out exactly like the steps I needed to take, all the documentation.

They had like a big document on like, 'what is FMLA?' Oh, grand, how do I

utilize that? …it was incredibly clear."

"HR blasted out emails repeatedly. Yeah, there was a lot of communication. And

my boss, although it wasn't actually his role was called up to be part of the

COVID response team. I kind of had an insider's perspective."

"There were lots of little things that they communicated at the same time, and

they communicated through video... it would get sent through my texts, if you're if

you're enrolled in the text notification. So, I would get a new text... for a while it

was like every day there were communications coming through."

"They had multiple channels of communication, they would send out group

emails, then they would be sending it out through the unit heads, like Deans and

chairs, Faculty Senate…. then during the faculty meetings, everybody was

reminded 'This is new.'"

Alternatively, many caregivers explained that employers did not thoroughly promote policy changes during to the pandemic nor were they reminded about existing accommodative policies that could help them, which added to the emotional burden they experienced.

"We had a staff meeting that I was lucky to have attended. It was not something

that my direct supervisor…offered to me. I became aware of it probably three or

six weeks after it was an option."

"You have to go ask. You have to go interpret it; you have to go make something

out of it. How do you do that with a fulltime job?"

Impacts of Identity

Gender. In allusions to the theory of gendered organizations, participants addressed how gender influenced their workplaces. Workplaces that were gendered in favor of men and had unreasonable expectations for employees with caregiving responsibilities. One participant expressed that her company lacked a compassionate

ethos. Her reasoning for why this did not exist was, "because it's a primarily male dominated leadership team." A caregiver who was in the military described the approach in her workplace to supporting caregivers as being limited to immediate supervisors. Those higher in the chain of command was not accommodative because "it's more of like the hard-headed guys that are, 'well you signed up for this. And this is your duty.'" This caregiver indicated that her boss was a woman but those in higher leadership positions were "guys."

Alternatively, those who worked with many women and in more caring-oriented fields, such as nursing and social work, described feeling supported at work. One caregiver who worked for a community nonprofit attributed the "understanding about motherhood and parenting and kids" philosophy in her workplace to the dynamic of the female-dominated staff, saying, "Because we have about 200 employees, and about 199 of them are women… They've not really talked about caregiving, but because they're aware of kind of women and flexible schedules, I think it was easier for me."

Race. Race was not often specifically mentioned as a facet of identity that impacted caregivers and their experiences with workplace policy during the pandemic. The only direct reference to race and workplace policy occurred when a white caregiver remarked on how her race likely helped her get her job at a supportive company with good benefits.

> *"Being a white woman…I think I have had a lot more opportunity than if I was a*
> *person of color. And that's more just anecdotally because I don't have any hard*
> *evidence showing that. But I think just overall that has affected the way that I was*

able to care for my mom, the opportunity that I had to even be working with the

company that I had in the first place."

Status in the Workplace. Status within the workplace was the most salient identity factor that contributed to caregiver experiences with workplace policy. Multiple caregivers mentioned their privilege and access to knowledge associated with their statuses in the workplace and recognized that their experiences were not universal. This was particularly true when it came to the flexibility that caregivers had with their jobs. Caregivers who had higher status in the workplace were able to work more autonomously, without being micromanaged like other colleagues with less power and status.

"If an administrative assistant was going through what I'm going through, that

professor would be breathing down her neck and making her life miserable."

Another caregiver described the privileges she had in her job role compared to others at her workplace as "definitely a class system." This caregiver was able to work flexible hours and could cancel work obligations for caregiving reasons, if necessary, as well as work remotely prior to the pandemic, whereas other employees with lower status within the workplace could not. One caregiver acknowledged that she was a supervisor at work and so she was more familiar with company policies, as well as legal rights that she had as an employee, stating, "I am a supervisor where I work. So, I know the law, right?" She also pointed out the advantages she had as a salaried rather than an hourly worker and someone with financial stability.:

"The type of job, the type of work you do, and your socioeconomic level… if I was
an hourly worker, if I was poverty level or close to it…socioeconomically, we're
doing well. I think if somebody in a different socioeconomic level, it would be... a
bit more of a struggle."

Summary

This chapter presented the analyzed findings from the 29 phenomenological qualitative interviews with working informal female caregivers during the coronavirus pandemic. Findings revealed the unique challenges, as expressed through caregiver burden, that caregivers have been facing during this time, as well as the role of workplace policy in mitigating this burden. Three major workplace policy categories emerged: flexibility, leave, and resources. Other workplace factors, such as manager support and workplace culture, were also important in understanding how caregivers managed work and care during the coronavirus pandemic. Certain identity-based differences in caregivers' experiences with workplace policies were salient; namely, gender and status within the workplace.

Chapter Five: Discussion & Conclusion

Introduction

This research explored how informal female working caregivers of older adults experienced the pandemic and how workplace policy impacted their experiences. The findings from this research were framed within the context of four types of caregiver burden - emotional burden, physical burden, financial burden, and work burden – and how workplace policy either addressed or disregarded these burdens. The theories of intersectionality, the theory of gendered organizations, and role conflict guided this research and findings both aligned and diverged from tenets of these theories.

Caregiver Burden

Caregiver burden provides an illustrative framework to better understand the difficulties in caring and working for working female caregivers. The coronavirus pandemic added another layer of complexity that influenced caregiver burden.

Emotional Burden

Emotional burden was expressed by many in this study and in multiple ways. Caregivers described feeling worried, anxious about the future, isolated, guilty, devalued, and overwhelmed. Though these are all emotions that caregivers could feel at any time, these feelings were likely exacerbated by difficulties experienced due to the pandemic. Beach and colleagues (2021) found that, when compared to non-caregivers, caregivers experienced more anxiety, depression, and fatigue and sleep disruption during the early

months of the pandemic and its associated lockdowns than they had prior to the pandemic.

When considering caregivers' emotional burden, the temporal nature of this research is key. People had been social distancing, at home, and in lockdown-type situations for approximately a year. All interviews were conducted during the winter to early spring months (February to April 2021), which also meant that isolation may have been exacerbated by the weather; in warmer months, caregivers had been better able to safely social distance and see others. There were immense barriers in access and connection with others outside of one's own household and caregivers highlighted feelings of loneliness and isolation that they and their care recipients were both experiencing; these challenges resulting from the loss of social and caregiving support were echoed in research done by Rokstad and colleagues (2021) on caregivers in Norway. It is not surprising that caregivers in this study were feeling emotionally drained and lonely without their usual social supports. In a nationwide poll, 65% of surveyed caregivers reported feeling isolated at least some of the time during the pandemic (Leggett et al., 2021).

Few people were vaccinated when interviews with caregivers started in February 2021. The rollout and eligibility for vaccines mostly centered around healthcare workers and older adults; most caregivers did not yet have access to the coronavirus vaccines, which caused caregivers to feel overlooked and devalued. Caregivers also felt devalued by their families, who failed to check in on them and how they were doing in their caregiving duties, depriving them of critical social support. Other qualitative research on

caregivers during the pandemic found that the simple effort of reaching out and offering support made a big difference for caregivers and how they coped with the pandemic (Rokstad et al., 2021); caregivers who lacked this may have struggled more.

Being overlooked and devalued as a caregiver extended into caregivers' attitudes about their workplaces as well. In alignment with the theory of gendered organizations, some caregivers described workplace cultures that disregarded their caregiving responsibilities outside of work, indicating that many organizations were still gendered in favor of men, who have traditionally been viewed as not having caregiving duties (Williams, 2010). One caregiver spoke about how her workplace had been "agnostic" to caregiving duties during the pandemic because of a male-dominated executive team. A caregiver who was a university professor described how her workplace would not accommodate her request to teach from home rather than in person during the pandemic because she, personally, was not the one with a condition that made her more vulnerable to contracting their coronavirus; she was caring for those who were more vulnerable. Another caregiver remarked on the inconsistency in policies across departments and different expectations that were dependent on the job role, not based on the working caregiver's needs. In contrast, one caregiver remarked that having a female-dominated staff at her company led to more awareness about caregiving responsibilities, though this awareness was typically focused on parenting rather than caregiving for older adults.

The unique environment of the pandemic meant that many caregivers were unable to set boundaries around caregiving. Due to the reduction in services (Giebel et al., 2021a; Rokstad et al., 2021) and danger involved in the presence of many different

people in the same space, caregivers frequently found themselves on their own in providing care. Recent estimates from a nationwide survey that looked at caregiving prior to the pandemic indicates that the average number of hours that a caregiver provides care is 24 hours per week, with 25% of all caregivers providing care for 40 hours or more every week (National Alliance for Caregiving & AARP, 2020). In this study, however, over a third of caregivers provided care for 51 or more hours every week, indicating that caregiving was more than a second fulltime job for many. This meant that caregivers had little time to themselves to rest and recharge. Whereas prior to the pandemic, caregivers may have had help with caregiving through services like respite and adult daycare, these services were no longer safe options for assistance with care. Research has shown that one mechanism for alleviating burden is tangible support for caregiving, such as in daycare and respite services (Vandepitte et al., 2016) and visits from other family members (Zarit et al., 1980) and friends (Rokstad et al., 2021), however both of these mechanisms of support were mostly eliminated during the pandemic. This reduced level of external support and care has been linked with less mental wellbeing for caregivers (Giebel et al., 2021a), which was reflected in the narratives shared by caregivers in this study.

Caregivers expressed concern over care recipients' lack of understanding of the pandemic and need for safety precautions. This difficulty was echoed in Giebel and colleagues (2021b) qualitative research, wherein both caregivers and care recipients were interviewed; caregivers had to put strict limitations on what care recipients were allowed to do out of caution for their safety and health. Not only did caregivers have to worry

about themselves and the anxiety of the unknowns about the virus, but they had to be hypervigilant for their care recipients, many of whom had vulnerabilities that made them more susceptible to the virus.

Intersectionality came into play when viewing the differential experiences of emotional burden for caregivers in this study. The one African American caregiver in this study described differences in her majority African American community during the coronavirus that other caregivers did not describe; namely, that she knew multiple people personally who had died from the coronavirus and that medical discrimination likely played a role in their deaths. This knowledge contributed to the worry and concern that she felt when she and her own mother were diagnosed with coronavirus; no other caregivers in the study reported contracting coronavirus nor did they know anyone who had died from coronavirus.

Three caregivers started to provide care during the pandemic, while four other caregivers greatly increased the amount of care that they provided. Though expectations to provide care for caregivers likely existed prior to the pandemic, the pandemic highlighted these expectations and obligations due to the lack of social support that caregivers both could and did receive from others. Four of the caregivers who were immigrants to the United States and provided care to immigrant parents spoke of cultural values that emphasized the importance of taking care of older members of the family. Miyawaki's (2016) research on the cultural differences among caregivers of Asian, Latine/Latinx/Hispanic, and non-Latine/Latinx/Hispanic white descent indicates the primacy of filial responsibility and obligation in caregiving duties for Asian and

Latine/Latinx/Hispanic caregivers. Other non-immigrant caregivers of color also indicated a strong ethos of filial responsibility in their caregiving practices, citing their cultural backgrounds as influential. Caregivers from non-Western European cultures may have felt less of a choice in caregiving and more pressure to provide care (Pharr et al., 2014), which can add to their burden. Caregivers from more collectivist cultures may struggle within the more rigidly individualistic American milieu (Markus & Kitayama, 1991; Pharr et al., 2014) and feel that they are unable to care for themselves within American culture that runs contrary to their cultural beliefs and customs. This may also mean that caregivers from non-western European cultures will be less likely to access professional caregiving services to assist in caregiving because the idea that caregiving must remain within the family has become strongly ingrained in them (Pharr et al., 2014), thereby increasing the likelihood that they feel overwhelmed. Other facets of American culture, such as a strong adherence to privacy, can make it even harder for immigrant caregivers to talk about the struggles that they were enduring, as one caregiver from India identified in this research. All of these factors may add to the emotional burden of being an immigrant caregiver during the pandemic.

Physical Burden

Emotional manifestations of burden impacted caregivers' physical health as well, causing physical burden. One caregiver described how she thought that the stress of taking on additional caregiving duties and moving her mother between states during the pandemic to be closer to her led to a "two-week mystery illness." Another caregiver spoke about how the anxiety she had from caregiving during the pandemic caused her to

gain weight. This caregiver is not alone in that; many people have gained weight over the course of the pandemic, with stress being a key contributor (Noguchi, 2021).

Caregivers described themselves as "exhausted," which is reflected in research that found that caregivers were more fatigued than non-caregivers during the pandemic (Park, 2020). Additionally, the lack of caregiving support from others that caregivers were enduring impacted not just emotional burden, but their physical burden as well. Research from prior to the pandemic backs this up; greater levels of emotional distress have been linked to poorer physical health in caregivers (Pinquart & Sorenson, 2007). As is the case for emotional burden, more social support has been linked to better physical health (Pinquart & Sorenson, 2007), which once again points to the detrimental effects of social isolation that have been necessitated for caregivers during the pandemic.

Financial Burden

The findings regarding financial burden in this study centered around three main topic areas: how caregiving impacted career trajectories and earning potentials, the cost of professional care, and the difficulties of being middle income. Three caregivers started working less during the pandemic due to increased care responsibilities. Two caregivers retired sooner than they anticipated. Of these five caregivers who reduced their working hours during the pandemic, two did not have college degrees and earned less than $25,000 in annual income. This mirrors a documented trend from the pandemic wherein low-wage and non-college educated workers have been hit particularly hard financially by the pandemic (Gould & Kassa, 2021; Kochhar, 2020; National Academics of Sciences, Engineering, and Medicine, 2021). Prior to the pandemic, caregivers reduced

their work hours as care responsibilities increased (Johnson & Lo Sasso, 2006), however, the pandemic provided an environment that accelerated this reduction in work hours by limiting social contacts who may have been able to help with caregiving when necessitated. Any reduction in work hits women hard financially, impacting retirement income and future earning potential (MetLife Market Institute, 2011), which can be especially detrimental when the gender pay gap is considered (AAUW, 2021). During the pandemic, nearly 60% of women have been concerned about their finances (Mullen, 2021).

Two caregivers discussed the impacts of caregiving during the pandemic on their career paths, preventing them from earning more money and attaining more prestigious titles and job responsibilities. Worldwide, women are underrepresented in top-tier managerial positions and this representation has only decreased during the pandemic (Karkee, 2021), which has implications for the future of women's careers. Research indicates that, worldwide, the coronavirus has set women back from achieving gender equity by nearly an entire generation, equivalent to 36 years (World Economic Forum, 2021).

The majority of caregivers in this study had incomes greater than $100,000. Despite this, caregivers still cited the high costs of professional care as barriers to getting more help than they had for caregiving. According to Genworth (2021), the annual cost for a home health aide is about $55,000; a private room in a nursing facility is about $106,000 annually. Even hiring someone to help with household chores around the house is close to $54,000 a year (Genworth, 2021). Caregivers with lower incomes expressed

the difficulties wrought by having fewer financial resources, speaking to the intersectionality of the caregiving experience and how their socioeconomic status influenced them and the resources that they lacked in providing care. Some caregivers were unable to afford professional care and knew that they may have to make drastic changes to their lives, like selling their homes, to afford care.

Financial burden was not limited to the lowest income-earners in this study; those who were middle-income discussed the challengers inherent in making too much money to qualify for Medicaid-subsidized services, but not enough to privately hire caregiving support on their own In contrast, caregivers with higher incomes and those from the United States could afford to cover assistive caregiving expenses, even if care recipients could not, reducing concerns about financial burden and preventing them from becoming overwhelmed with the stressors of caregiving. Immigrant caregivers discussed the additional costs of caregiving for them, as some of their care recipients were not American citizens and were therefore unable to access publicly subsidized insurance like Medicare and Medicaid until they were in the United States for at least five years (Kaiser Family Foundation, 2021). Caregivers with care recipients who were American citizens talked about the benefits they had due to having "good insurance" like Medicare.

Work Burden

Experiences of work burden can be understood within the context of role conflict and overlap with financial burden. Caregivers who reduced their working hours during the pandemic experienced conflict between their caregiver and worker roles such that caregiving limited their ability to execute their roles as workers as they had prior to the

pandemic and inhibited their earning potential. This was also the case for the caregivers whose caregiving duties impeded them from attaining promotions and greater responsibility at work.

Caregivers also spoke about how care recipients interrupted them during their workdays, which prevented them from being able to fully concentrate. Competing demands for a working caregiver's time, attention, and energy were commonplace, which seemed to be exacerbated by the shift to working from home. Biddle and Thomas (1966) discuss how role conflict can "create personal confusion, anxiety, and ambivalence for the individual, to say nothing of the many possible social dysfunctions of the conflict" (p. 273), which speaks to the burden that many working female caregivers faced in trying to provide care and work during the pandemic. This may especially be the case when the workplace is gendered more in favor of men and unsupportive of caregiving activities, as the theory of gendered organizations suggests.

The Role of Workplace Policy

Accommodative workplace policies can begin the work of "ungendering" workplaces by recognizing that employees have rich, full lives, of which being an employee is only one part. Employers buck the prescriptions of the theory of gendered organizations by acknowledging that their employees have significant roles and responsibilities outside of work. Through offering helpful policies, employers can reduce role conflict and the level of burden that working caregivers face. Caregivers spoke about the policies available in their workplaces and what helped and hindered them in balancing work and caregiving during the pandemic.

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Flexibility

Flexibility in the workplace was highly endorsed and mitigated emotional and work burden for caregivers in this study. The words "flexible" and "flexibility" in relation to work were mentioned 52 times by caregivers across 18 interviews. Flexibility included the ability to work from home, which enabled household tasks and small errands to be done during the day, as well as control over work schedules, such as when to start and stop work and the ability to catch up on work outside of traditional 9 am-to-5pm work hours. This flexibility reduced emotional and work burden for caregivers in this study. Similarly, Hokke et al. (2021) found associations between workplace flexibility, such as a flextime schedule and remote work, with reduced fatigue and burnout for working parents. Other research has found that flexible workplace provisions are associated with feelings of autonomy, control, and competence for workers (Gajendran and Harrison, 2007; Galanti et al., 2021; Thomas & Ganster, 1995), which further speaks to the positive benefits that flexible policies can have for working caregivers. These feelings are associated with decreased levels of depression and physical burden (Thomas & Ganster, 1995). Contrary to the Theory of Gendered Organizations, many caregivers praised their workplaces as being accommodative and more oriented to the needs of caregiving women during the pandemic due to the increased flexibility that they had.

"Work from home" is known by many synonymous phrases: "telecommuting," "teleworking," and "remote work" (Crandall & Rao, 2005) are some of its most common appellations. However, during the pandemic, the ability to work outside of the office truly became "work from home" as individuals' homes and families became the only safe

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environmental context for work and socialization. Working from home allowed caregivers to protect themselves and their care recipients from contracting and spreading the coronavirus, thereby reducing emotional burden, in line with extant research findings (Galanti et al., 2021).

While many caregivers liked working from home and the flexibility this offered, others struggled with the lack of separation between home and work life, which made role conflict ever-present; Galanti and colleagues (2021) research during the pandemic also confirms these findings. As the home and the office became the same space for many, home was no longer a respite from work and work was no longer a reprieve from home stressors like caregiving. Caregivers expressed the feeling of always being "on," as well as unable to concentrate on work with other people, such as care recipients, nearby. Caregivers who struggled with working from home appreciated the ability to return to the office at least a few days every week when that became a safer option.

Parttime work was a workplace policy that some caregivers used to better manage work and caregiving. Though there is no one uniform definition of parttime work (U.S. Department of Labor, n.d.), five caregivers worked 30 hours or less at the time of interview. Though these caregivers seemed relieved to be able to work parttime, they remarked on the lack of benefits that they had due to their parttime status. Workplaces are bound by few laws that require them to provide benefits like health insurance and retirement plans to parttime employees. If employees work under 30 hours a week, workplaces are not required to offer them health insurance (Patient Protection and Affordable Care Act, 2010). If employees work less than 1,000 hours per year, they are

not eligible for an employer's retirement plan (ERISA, 1974). Other caregivers would have been interested in parttime work as an option to help them better manage the emotional and work burdens of caring and working but mentioned that working parttime would exacerbate financial burden for them, as they would be forgoing fulltime payment and aforementioned benefits.

Leave

There is a plethora of leave options that workplaces could offer; this research addressed four specific types of leave: federally mandated FMLA, paid time off (also commonly known as "vacation time"), sick leave, and paid family leave. Among caregivers, there was some confusion around leave policies and whether paid leave was available to take time off work for caregiving purposes. This confusion spoke to the overall lack of clarity that caregivers had about what workplace policies were available to them.

Policies were also set up in such a way that some caregivers had to choose between caregiving and taking time for themselves outside of work by grouping vacation time, sick leave, and leave that a caregiver would take for caregiving purposes into the same leave policy benefit. If a caregiver used all their leave for caregiving, they could then be left without any vacation or sick time for themselves.

FMLA requirements disproportionately exclude women and people of color from coverage (Heymann et al., 2021) and this leave is unpaid. In this study, at least five caregivers did not have access to FMLA, as their workplaces were too small, or they

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worked for themselves. Thus, FMLA was not something that could help them with their caregiving duties during the pandemic or otherwise.

The United States is one of only 11 countries that does not have a national paid sick leave policy (Heymann et al., 2021). Two caregivers in this study had abundant sick leave, which they praised; another caregiver discussed the newly implemented sick leave policy in her workplace. The FCCRA sought to ensure sick leave for workers who did not previously have it by mandating up to 80 hours of paid sick leave for every worker who was either quarantining, diagnosed with, or caring for someone with coronavirus. This policy was viewed as a boon for workers and public health (Pichler et al., 2021), even if there was some misunderstanding among caregivers in this study regarding whether this policy was federally sponsored or solely workplace specific.

In addition to not having a federal paid sick leave policy, the United States is also one of only six countries without a federal paid family leave policy (Miller, 2021). Nine caregivers in this study were fortunate to live in states or work for companies that provided paid leave. One caregiver who used paid leave for caregiving exclaimed how grateful she was for it. Studies have found associations between access to paid family leave and less mental stress among parents (Irish et al., 2021) and greater financial security among workers who took paid leave than those who had similar needs for leave but either did not take leave or took unpaid leave (Goodman & Schneider, 2021), indicating that paid family leave can alleviate emotional and financial burden.

One caregiver mentioned a special paid leave policy for caregivers that her workplace had implemented specifically during the pandemic titled "COVID pay." This

policy allowed her to continue to be paid for the same number of hours that she worked

prior to the pandemic even if she was now providing care to her children or her

grandmother during some of those hours. This policy signified a step this company took

towards ungendering their workplace by acknowledging that workers had lives outside of

work and that caregiving had increased for many of its employees during the pandemic.

This caregiver spoke glowingly of her company due to this policy and the recognition

that they had of caregivers during the pandemic. However, this caregiver also noted that

the special payment provisions offered by this policy were ending soon after the

interview, which was causing her to have anxiety; this policy was not permanent.

Despite some positive endorsements of paid leave by caregivers in this study, not

everyone was equally as excited about the paid leave that they had. One caregiver who

lived in a state with paid leave did not know that she had access to paid leave through the

state. Others who had paid leave were not satisfied with the paid leave provision that they

had, citing the payment amount, which was only a fraction of the caregiver's income, and

the amount of paid time off work (only six of the 12 weeks offered by FMLA would be

paid) offered by their companies' paid leave policies as insufficient. Further, only 31% of

the caregivers had paid leave in the first place, indicating that paid leave was a policy that

needed to be more expansive. Without a comprehensive national paid family leave plan,

workers can easily become exploited and subject to the whims of where they live or their

workplaces.

Resources

Out of the three types of workplace policies mentioned as helpful to working caregivers, resources available through programs like EAPs seemed the least helpful for caregivers in this study. Per the Society for Human Resource Management (SHRM), employee assistance programs are described as "work-based intervention programs designed to assist employees in resolving personal problems that may be adversely affecting the employee's performance" (n.d.). EAPs started as workplace programs to address alcoholism among workers and have since been expanded to provide resources that address problems such as relationship issues, financial struggles, substance use disorders, and mental health challenges (Masi, 2011; U.S. Office of Personnel Management, n.d). With the increase in women's involvement in the workforce and the subsequent rise in families with two working parents, childcare and even eldercare have come under the purview of EAPs (Masi, 2011).

Using the frame of the theory of gendered organizations, because an employee's primary responsibility and concern should be their work, the purpose of any benefit an employer provides is to ensure their employees' wellness so that they can continue to be good workers. Employers want to be sure that if they invest in their employees in a way that also benefits them *outside* of work that they are getting a good return for this investment *within* the workplace as well by having a worker who is able to be physically and mentally present at work. Though intended to alleviate emotional, financial, and work burden so caregivers could focus on their work during work hours, caregivers in

this study were disappointed that their EAPs did not offer more support or resources for caregiving for older adults; the focus of their EAPs seemed to be on childcare and geared towards workers with children. This lack of recognition for caregiving responsibilities caused caregivers to once again feel devalued and overlooked. Fuller and Raman (2019) also found that employers placed concerted focus on parenting but failed to account for other forms of caregiving that occur over the course of an employee's career, and thus, do not offer benefits that would be most helpful to them.

Supportive Supervisor and Workplace Culture

Policies that support caregivers in the workplace may not matter if there is not institutional support and recognition for employees' responsibilities outside of the workplace. Eleven caregivers mentioned how much they valued having a supportive supervisor and how this support was crucial to them in being able to balance work and caregiving duties. Research has emphasized the importance of the role of supportive supervisors in minimizing role conflict for workers (Greenhaus et al., 2011; Thomas & Ganster, 1995). Caregivers also emphasized the importance of a workplace culture that was supportive of family and work-life balance. Others mentioned that there was a shift in the culture of their workplaces in such a way that recognized care duties, which they appreciated.

Not all caregivers felt supported by their workplaces. Two caregivers described their discomfort in disclosing their caregiving status to superiors at work, as they were fearful of the repercussions that this may have on their employment. Similarly, 55% of employee survey respondents in Fuller and Raman (2019)'s research on company

culture felt that caregivers had slower career progression than non-caregivers and were viewed as less committed to work; over half of employees surveyed affirmed that their company's culture did not foster the career growth of caregivers as well as it could have.

Impacts of Identity

The findings of the impact of workplace policy on working caregivers cannot be viewed in a vacuum; they must be viewed in the context of caregivers' identities. Though the research focused on caregivers' current social locations, pre-existing facets of identity led them to where they were in terms of both caregiving and working. The most salient aspects of identity that participants acknowledged were their gender and their statuses within the workplace. In contrast to extant research, race was not a notable contributing factor to caregivers' experiences with workplace policy, which was likely due to the lack of racial diversity within the participant sample. Caregivers contrasted their gender and identity as caregivers with the male-dominated leadership at their companies and remarked on how this contributed to them feeling a lack of support in their "feminine" duty as caregivers for loved ones.

In this study, more than 70% of participants had at least a college degree. An individual's income, job, and job status are highly predicated on their access to and level of education (Torpey, 2020, 2021). Those with a college degree or more education are the most likely to have access to benefits in the workplace and have higher pay than those without this level of education (Pew Research Center, 2016; Torpey, 2020, 2021).

Strengths of this Research

This research benefited from several strengths that set it apart from related research. One, it took a broad view of what was considered "caregiver burden." Quantitative measures often attempt to capture burden using precisely defined items, written in ways that may not resonate with caregivers (Bastawrous, 2013). This research did not presuppose what caregivers would define as burden, but rather let caregivers describe their experiences and the hardships they faced. This also served as a more culturally responsive approach to caregiver burden, as individuals from non-western, Eurocentric cultures may conceptualize and describe burden differently (Calderon & Tennstedt, 1998).

Relatively few studies have taken a qualitative approach to caregivers' experiences during the pandemic (Lightfoot et al., 2021). Prior research has cited the need for more qualitative investigation into the phenomenon of caregiver burden (Bastawrous, 2013). This research allowed caregivers to qualitatively describe their burden and the emotions that defined it. This methodology ensured that caregivers' words and voices were front in center when describing the dilemmas that pertain to them. The caregivers in this study shared profound insight and rich descriptions of the caregiving experience that cannot be captured by quantitative research.

Not only does this study explore caregiver burden with an underused methodological approach, but this research also looks at caregiver burden qualitatively within the context of the coronavirus pandemic. Lightfoot and colleagues (2021) conducted qualitative research on caregivers' concerns and positive experiences during

the pandemic in the United States and noted that few studies had studied caregivers amidst the pandemic qualitatively. This researcher was only able to find two additional qualitative studies on caregivers' experiences during the pandemic: Rokstad and colleagues (2021) investigated the impacts of the pandemic on spousal dementia caregivers in Norway and Vaitheswaran and their team (2020) qualitatively assessed the mental health issues and support needs of dementia caregivers in India during the pandemic. None of these three studies looked specifically at working caregivers nor how working and caregiving interacted during the pandemic. This research fills a novel gap in the literature on how dual societal roles played out in the context of the pandemic.

Caregivers lived in fourteen different states (including Washington D.C.) that represented every region of the United States. Given the subjective nature of the impacts of the coronavirus pandemic, it is a strength that this research had geographic diversity among participants and reflected views from caregivers living in urban, suburban, and rural areas that were differentially impacted by the pandemic. Further, caregivers worked in a wide array of industries and types of companies, creating a broad representation of types of workplaces and working arrangements.

Limitations

Despite the many strengths of this research, there are limitations that exist, as in any study. This research queried caregivers at one specific point during the pandemic; given how long the pandemic has lasted, the views represented in the findings can only be extrapolated to that point in time. It is likely that caregivers' perspectives, struggles, and coping mechanisms have evolved throughout the pandemic.

Methodologically, there were a few limitations. Given challenges with recruitment, only 24% of the sample were women of color. Recruitment of racially diverse samples of caregivers has been a consistent challenge for researchers, largely owing to historical legacies of harm that researchers have inflicted upon minoritized communities and general distrust due to this harm (George et al., 2014); it is a probable conjecture that these factors impacted recruitment for this study. Additionally, the language used to advertise the study – namely, the use of the word "caregiver" in flyers, may not resonate with some people of color and those who come from cultural backgrounds with a strong sense of familism who see caregiving as a filial responsibility and not as a separate societal role (Makin, 2019; Pharr et al., 2014), thus deterring these individuals from participating.

The inability to recruit many caregivers of color is likely due to this researcher's identity as a white woman who has primarily white social and professional contacts. Given the pandemic environment, this researcher was limited in her ability to advertise the study outside of her existing social and professional circles. When conducting research with individuals that differ from the researcher's identity, it is common practice to engage a gatekeeper to assist in recruiting a diverse sample (Aaron, 2016) and base recruitment within the communities in which participants are desired (George et al., 2014). However, the virtual environment of the pandemic limited this researcher's ability to create new relationships with individuals who could help with recruitment and to meet participants in person within their own communities. Further, the pandemic has had disproportionately negative impacts on Black and Latine/Latinx/Hispanic communities,

as measured by both health and economic indicators (Asfaw, 2021; Kochhar, 2020; Shiels et al., 2021; Wrigley-Field et al., 2021). It is likely that participation in research was not a priority for many caregivers who were facing the consequences of systemic racism and medical discrimination that exacerbated the harm of the pandemic within communities of color (CDC, 2021c). However, the lack of racial diversity in the sample limits the ability to view findings through an intersectional lens, as race is a key factor identity that contributes to differential outcomes among caregivers (Dilworth-Anderson et al., 2002; Navaie-Waliser et al., 2001). Future research would benefit from focused efforts to racially diversify the sample of working caregivers to reflect caregiver experiences more accurately.

This sample of caregivers was, on average, highly educated, with 72.1% having at least a four-year college degree and nearly half (44.8%) possessing a postgraduate degree. By contrast, national data suggests that only 21% of caregivers of older adults have a college degree and only 15% have a postgraduate degree (National Alliance for Caregiving & AARP, 2020), indicating that this sample of caregivers was much more educated than the average caregiver. Given that level of education and income are highly correlated (Torpey, 2021; Wolla & Sullivan, 2017), this sample was also relatively high income, with more than half of the sample (51.7%) having incomes over $100,000. For comparison, the median household income of caregivers based on data gathered in a national survey was $67,500 (National Alliance for Caregiving & AARP, 2020). Though some caregivers commented on the influences of their education and income and how this affected caregiving, future research would benefit by exploring caregiver

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perspectives on burden during the pandemic from a more socioeconomically diverse group of caregivers that had education levels more in line with national averages.

Directions for Future Research

As researchers, we have been pushed to "make lemonade out of lemons" when the coronavirus pandemic struck. It was necessary for research to pivot to new virtual formats and for researchers to rethink their methodologies to protect public health while preserving research integrity. With this, new opportunities and lines of research inquiry presented themselves; all research done that integrates the context of the pandemic environment will be "novel" given that the world has never endured a pandemic such as this in the modern age. Given this, there are numerous directions for future research that can extend from this study.

As this study was cross-sectional, there was little ability for caregivers to assess how caregiving and working changed over the course of the pandemic. Future research could look at caregiving experiences in a post-pandemic context and explore the evolution of working and caregiving within this socioenvironmental evolution.

In this research, the gender of caregivers was held constant to allow for feminist inquiry and theorizing to take place. However, male caregivers do make up a substantial portion of the population (National Alliance for Caregiving & AARP, 2020) and it is worthwhile to compare how they have experienced the pandemic in contrast to female caregivers.

National studies of caregivers generally breakdown differences in caregiving along the gender binary (e.g., National Alliance for Caregiving & AARP, 2020).

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However, more than two genders exist. Nonbinary and genderqueer individuals have been advocating for greater representation in all facets of society and this representation should extend into caregiving research. A cursory search using the keywords "nonbinary caregiver" and "genderqueer caregiver" revealed no studies on caregivers who are nonbinary or genderqueer; results only revealed articles on providing care for transgender, nonbinary, and genderqueer individuals. An AARP report (2021a) on demographic trends in caregiving among LGBTQ older adults finds that 61% of the 250 transgender and nonbinary individuals surveyed have served as caregivers, with transgender and nonbinary individuals being more likely than cisgender gay, bisexual, and lesbian men and women to have taken a leave of absence from work or quit their jobs altogether to provide care. Few other details or insights into these differences or the experiences of nonbinary and transgender caregivers appear to exist in the public domain. Issues relating to nonbinary and genderqueer caregivers likely differ from those who are cisgender given discrimination and marginalization that nonbinary people face in many facets of their lives (Bockting et al., 2013; Bradford et al., 2013). Future research would benefit from looking at the experiences of nonbinary and genderqueer caregivers and their perceptions of caregiver burden, how these perceptions may have been affected by the pandemic, and if workplace policy has accommodated their needs.

Facets of the caregiving scenario not explicitly queried in this study are highly relevant to caregiver burden, such as the care recipient's level of debility and need (Riffin et al., 2019), the care recipient's diagnosis (del-Pino-Casado et al., 2019; Riffin et al., 2019), the quality of relationship between the caregiver and the care recipient (Gupta,

2000), the caregiver's health status (Irani et al., 2021), and how long the caregiver has been providing care (Park, 2020). For example, those who have been providing care for longer may have had more time to adjust to caregiving and see caregiving more as a typical part of their lives. These caregivers may have internalized caregiving and may see their identities as caregivers as different than those who are newer to caregiving, which, in turn, impacts how they experience caregiver burden. Though caregivers touched on some specific dynamics of the caregiver scenario during their interviews for this study, none were considered in-depth when looking at how caregiver burden and workplace policy interacted, as they were not germane to the research questions. Future research could delve more deeply and compare caregiver experiences based on various facets of the caregiving situation.

This study was purely qualitative in nature. As caregiver burden was subjectively defined, a standardized quantitative measure of caregiver burden could add to this research by allowing comparison of caregiver burden across research participants. Future research could involve the use of a standardized caregiver burden scale, such as the Zarit Burden Interview or any of its derivations (Bedard et al., 2001; Zarit et al., 1980), to enhance findings.

Opportunities for Workplace Policy and Systemic Reform

Caregiving emphasizes the interconnected nature that links all of us. Rosalynn Carter (Family Caregiving Issues, 2011) stated that "there are four kinds of people in the world; Those who have been caregivers; Those who are currently caregivers; Those who will be caregivers; And those who will need caregivers." This statement speaks to the

prevalence of caregiving within our society. Informal caregivers provide care and

protection for some of the most vulnerable members of our society – those with advanced

age and disabilities that prevent individuals from functioning independently. The work

that caregivers do is often hidden and unrecognized publicly, as it occurs within family

systems and smaller social structures, within the privacy of homes. Informal caregivers

continue to work outside of their caregiving duties, oftentimes even as their caregiving

obligations increase. Existing research shows that almost one quarter oof caregivers of

older adults reported not feeling supported in their caregiving duties by their workplace

during the pandemic (Rosalynn Carter Institute for Caregiving, 2020).

The future of care likely lies in building a community and ethos of care. In fact,

many have written about how it is human nature (regardless of gender) to care. As Mia

Birdsong (2020) writes,

> The thing is, we love to help. Our best self gets a positive feeling from supporting others. It's a feeling that is not about the gratitude that we receive or the points we earn, but an alignment with love and care that fills us. When we see someone experience relief or ease or happiness because we helped them, we are filled. It also helps remind us that we are not out here alone, we don't achieve or thrive, or survive or get by, on our own. (p.16)

Care is an innate human instinct, and this instinct should not be discouraged in the

workplace. One of the ways that humans have gotten so far as a species is that we have

developed sophisticated ways to care for one another when sick or otherwise

incapacitated. Rather than frame caregiving as a time-limited problem, exclusive only to

those with young children or older adult caregiving responsibilities, it should be seen as

something that can happen for anyone at any time; it is a fallacy to believe that there is an

"end" to caregiving during the life cycle. Families are not something that are unique to a few of us; nearly everyone would endorse a family of some type, be that chosen or linked by blood. The family structure developed to perpetuate our society and it is a disservice to pretend as though it does not exist in the workplace.

In this research, caregivers described themselves as "lucky" if their workplace understood and supported caregiving. There was a lack of expectation that workplaces would provide support for caregiving; many did not anticipate getting any help. In short, they anticipated a lack of "culture of care." However, rather than empathy and compassion for caregiving being the exception for companies, it should be the norm. It is not an anomaly; nearly 29 million workers are also informal caregivers at home (National Alliance for Caregiving & AARP, 2020). Caregivers should not feel "lucky" that employers understand their caregiving responsibilities; the whole notion of what defines an "ideal worker" needs to change and transform from what was initially suggested by Acker in the theory of gendered organizations. As Ai-Jen Poo (2020), founder and director of Caring Across Generations, an advocacy organization for caregivers, says, "people want to work, people want to take care of their families; both those things are good things. Why wouldn't we set up public structures and systems that support that?"

The coronavirus pandemic has presented new opportunities for innovation in the workplace that will better support working caregivers. The pandemic has laid bare the fact that employees are not solely workers – they are individuals with whole lives and important responsibilities outside of work. As Erica Pimentel (2020) wrote, the pandemic has made "the personal visible." It would be nearsighted to believe that pandemic

changes should not remain as permanent accommodations that make work-life balance for working female caregivers easier.

The first place to start to provide more supportive workplace policy for working caregivers would be through a needs assessment that first identifies caregivers in the workplace and then asks what would be most helpful to them. Caregivers in this study mentioned that they were not open about their caregiver status at work out of fear of negative repercussions or that employers would not be supportive of them. Though these caregivers had some accommodative workplace policies, none were tailored specifically to their needs as caregivers and were not as helpful as they could have been. Fuller and Raman (2019) found that there were low usage rates for workplace policies that employers anticipated would be most helpful, meaning that employers were wasting money on benefits that employees did not want or use. Further, employers often fail to provide policies that employees needed to help them with caregiving duties (Fuller & Raman, 2019), which suggests that employers were not in tune with their employees nor responsive to their needs. Working caregivers are not a monolith and individual caregivers may differ in their needs, so it is critical that the workplace is receptive to what their specific caregiving employees want.

Workplace adaptability speaks to the flexibility and options that caregivers in this research identified as wanting from their employers. Though most caregivers in this study reported that they liked working from home, there was diversity of opinions and perspectives on this given the intersectional nature of each caregiver's unique caregiving situation. By offering options to employees, companies could be most responsive to a

broad swath of working caregivers. Since May 2020, multiple well-known and large corporate employers have transitioned to permanent optional work-from-home policies in response to their employees' preferences (Buildremote, 2021).

With leave policies, it is critical that employers make clear what types of leave they offer and what each type can be used for. Rather than lumping all paid leave (e.g., vacation time, sick leave, paid family leave, etc.) together under one broad policy, companies should delineate out different types of leave that are available. This would allow caregivers to maintain time that they want or need off for themselves, even if they also need to take leave to provide care, thus reducing the chance of excessive caregiver burden and burnout.

Recent legislation has taken on the matter of paid family leave and expanding eligibility for federally mandated leave beyond what is offered by FMLA. In the recent budget reconciliation bill, progressive Democrats proposed 12 weeks of paid leave that comprehensively covered nearly every worker, including those who were gig workers and self-employed, however the provision was reduced to four weeks in the process of negotiations aimed at getting the bill to pass (Miller, 2021). Though a federal paid leave policy would be ideal and ensure that every worker in the United States were covered, individual workplaces could take up the helm if this policy fails to pass. Currently, only 23% of civilian and private industry workers and 26% of state and local government employees have access to paid leave (United States Bureau of Labor Statistics, 2021). Expansion of paid family leave to more workplaces, as well as every worker in their

respective workplaces, could help working caregivers remain employed, particularly those who are low income (Byker & Patel, 2021; Wolff et al., 2019).

When assessing resources offered through EAPs, companies need to be cognizant of caregiving responsibilities for older adults and not solely focused on the needs of employees with childcare responsibilities. In this research, caregivers discussed the high cost of professional care and cited this as a reason that they had to take on more caregiving responsibilities themselves. Similarly, Fuller and Raman's (2019) research found that caregivers often left the workplace because professional care was too expensive. Another common reason was due to the difficulty and barriers involved in finding good professional care (Fuller and Raman, 2019). EAPs could assist caregivers by providing comprehensive case management services that include referrals to adult daycare and home healthcare programs, as well as subsidize the cost of these services in the same way that they subsidize insurance by cost-sharing with employees.

Lastly, policies need to be universal across the workplace, regardless of an individual's job title or rank within the workplace. A modern-day caste system is instituted by differentiating access to benefits based on workers' statuses in the workplace. Individuals' unique identities, opportunities, and privileges often play out in the workplace and are further perpetuated by ongoing inequalities between different job ranks and titles. Universal access to benefits in the workplace would be a significant step towards reducing inequities among different stratifications of workers within the workplace (Joshi et al., 2020). The nature of some jobs may not allow for the same

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policies to pertain to every job type; in these instances, approaches that can make the different job functions and roles as equitable as possible should be pursued.

The implications for both policy and systemic change generated by this research are not solely intended to serve female caregivers of older adults. It is predicted that solutions and policy fixes that support and sustain caregivers will not only benefit caregivers of older adults, but all of those who provide care for anyone of any age. This dissertation is intended to illuminate and highlight caregivers as a population that is infrequently mentioned in the public sphere, but its implications can contribute to positive change for many others balancing work and care of all types.

Summary

This chapter discussed the relevance of the findings from this study and how they can be applied to creating systemic change. Strengths, limitations, and directions for future research were also acknowledged as important facets of the study, with implications for how this research can be improved in the future.

Conclusion

This research study explored the experiences of working female caregivers during the coronavirus pandemic. Caregivers shared insights on the impacts of the pandemic on their working and caring roles, as well how workplace policy interacted with these roles and caregiver burden. Experiences of emotional burden were particularly acute, with caregivers' expressing feelings of obligation, worry and concern, isolation, and being devalued. Workplace policies that provided flexibility and generous and compensated leave were appreciated as supports that mitigated burden, with the acknowledgment that a

workplace climate that fostered socioemotional support from company leadership and an

overall supportive workplace culture were critical factors that made working and caring

during the pandemic manageable. Without these characteristics, caregivers were inclined

to feel overwhelmed and overlooked as employees with caregiving responsibilities. Other

workplace policies that companies offered that may have seemed supportive, such as the

ability to work parttime and offering EAP resources, were more symbolic than effectual

when they were not specifically geared towards the needs of caregivers of older adults. In

the future, it is critical that policies are created with equitable considerations for

caregivers to be most impactful and to nurture a culture of care in the workplace.

References

A Better Balance. (2021). *Comparative chart of paid family and medical leave laws in the United States.* https://www.abetterbalance.org/resources/paid-family-leave-laws-chart/

Aaron, C. S. (2016). Recruitment of African Americans with Type 2 Diabetes who care for persons with dementia: Lessons learned. *Clinical Nursing Research*, *25*(1), 3-8. https://doi.org/10.1177/1054773815621217

AARP. (2020, February 4). *Can I get paid to be a caregiver for a family member?* https://www.aarp.org/caregiving/financial-legal/info-2017/you-can-get-paid-as-a-family-caregiver..html?intcmp=AE-CAR-CRC-LL

AARP. (2021a). *The state of LGBTQ dignity 2020: A supplement to maintaining dignity pre-COVID 19.*

https://www.aarp.org/content/dam/aarp/research/surveys_statistics/life-leisure/2021/lgbtq-community-dignity-2020.doi.10.26419-2Fres.00379.001.pdf

AARP. (2021b, June). Caregiving out-of-pocket costs study.

https://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2021/family-caregivers-cost-survey-2021.doi.10.26419-2Fres.00473.001.pdf

AAUW. (2019). *The simple truth about the gender pay gap: Fall 2019 update.*

https://www.aauw.org/app/uploads/2020/02/Simple-Truth-Update-2019_v2-002.pdf

AAUW. (2021). The simple truth about the gender pay gap: Fall 2021 update.

    https://www.aauw.org/app/uploads/2021/09/AAUW_SimpleTruth_2021_-

    fall_update.pdf

Acker, J. (1990). Hierarchies, jobs, bodies: A theory of gendered organizations. *Gender*

    & Society,4(2), 139-158.

Acker, J. (1992). Gendering organizational theory. In Shafritz, J.M., Ott, J.S., & Jang,

    Y.S. (Eds.), *Classics of organization theory* (pp. 420-428)*.* Cengage Learning.

Acker, J. (2006). Class questions, feminist answers. Rowman & Littlefield Publishers,

    Inc.

Acosta, R.A. & Wiatrowski, W.J. (2017, September). *National Compensation Survey:*

    Employee benefits in the United States, March 2017. U.S. Bureau of Labor Statistics.

    https://www.bls.gov/ncs/ebs/benefits/2017/ebbl0061.pdf

actiPLANS. (2020). *Employee time off: Most common and unusual leave types in 2020.*

    https://www.actiplans.com/blog/leave-type

Adamaczyk, A. (2021, October 28). *Here's what's in the Democrats' $1.75 trillion Build*

    Back Better plan. CNBC. https://www.cnbc.com/2021/10/28/whats-in-the-democrats-

    1point85-trillion-dollar-build-back-better-plan.html

Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014).

    Caregiver burden: A clinical review. *Journal of the America Medical*

    Association, 311(10), 1052-1060. https://doi.org/10.1001/jama.2014.304

Administration for Community Living. (2021, September 22). *RAISE Family Caregivers*

    Act initial report to Congress. https://acl.gov/RAISE/report

American Rescue Plan Act of 2021, Pub. L. No. 117-2 (2021).

   https://www.congress.gov/117/bills/hr1319/BILLS-117hr1319enr.pdf

Ang, S. & Malhotra, R. (2018). Expressive social support buffers the impact of care-

   related work interruptions on caregivers' depressive symptoms. *Aging & Mental*

   Health, 22(6), 755-763. https://doi.org/10.1080/13607863.2017.1317329

APM Research Lab. (2020, November 12). *The color of coronavirus: COVID-19 deaths*

   by race and ethnicity in the U.S. https://www.apmresearchlab.org/covid/deaths-by-

   race

Asfaw, A. (2021). Racial disparity in potential occupational exposure to COVID-19.

   Jounrla of Racial and Ethnic Health Disparities. https://doi.org/10.1007/s40615-

   021-01110-8

Asher, L.J. & Lenhoff, D.R. (2001). Family and medical leave: Making time for family is

   everyone's business. *The Future of Children, 11*(1), 114-121.

Au, A., Lau, K.M., Koo, S., Cheung, G., Pan, P.C., & Wong, M.K. (2009). The effects of

   informal social support on depressive symptoms and life satisfaction in dementia

   caregivers in Hong Kong. *Hong Kong Journal of Psychiatry, 19*, 57-64.

Badana, A.N.S., Marino, V., & Haley, W.E. (2019). Racial differences in caregiving

   variation by relationship type and dementia care status. *Journal of Aging and Health,*

   31(6), 925-946. https://doi.org/10.1177/0898264317743611

Barnett, R.C. & Baruch, G.K. (1985). Women's involvement in multiple roles and

   psychological distress. *Journal of Personality and Social Psychology, 49*(1), 135-

   145.

Barnett, R.C. & Hyde, J.S. (2001). Women, men, work, and family: An expansionist

theory. *American Psychologist, 56*(10), 781-796. https://doi.org/10.1037//0003-

066X.56.10.781

Bartash, J. (2020, August 7). *The U.S. has only regained 42% of the 22 million jobs lost

in the pandemic. Here's where they are.* MarketWatch.

https://www.marketwatch.com/story/restaurants-and-retailers-have-regained-the-

most-jobs-since-the-coronavirus-crisis-but-theres-a-catch-2020-08-07

Bartel, A.P., Kim, S., Nam, J., Rossin-Slater, M., Ruhm, C., & Waldfogel, J. (2019,

January). *Racial and ethnic disparities in access to and use of paid family and

medical leave: evidence from four nationally representative datasets.* U.S. Bureau of

Labor Statistics. https://doi.org/10.21916/mlr.2019.2

Barzilay, A.R. (2019). Discrimination without discriminating? Learned gender inequality

in the labor market and gig economy. *Cornell Journal of Law and Public Policy, 28,*

545-566.

Bastawrous, M. (2013). Caregiver burden: A critical discussion. *International Journal of

Nursing Studies, 50*(3), 431-441. https://doi.org/10.1016/j.ijnurstu.2012.10.005

Bateman, N. & Ross, M. (2020). *Why has COVID-19 been really harmful for working

women?* The Brookings Institute. https://www.brookings.edu/essay/why-has-covid-

19-been-especially-harmful-for-working-women/

Bauer, E. (2021, April 21). Why Biden's infrastructure plan is not the answer to long-

term care funding needs. *Forbes.*

https://www.forbes.com/sites/ebauer/2021/04/16/why-bidens-infrastructure-plan-is-not-the-answer-to-long-term-care-funding-needs/?sh=772c6de568a5

Beach, S. R., Schulz, R., Donovan, H., & Rosland, A. M. (2021). Family caregiving during the COVID-19 pandemic. *Gerontologist*, *61*(5), 650–660. https://doi.org/10.1093/geront/gnab049

Bédard, M., William Molloy, D., Squire, L., Dubois, S., & Lever, J. A. (2001). The Zarit Burden Interview: A new short version and screening version. *The Gerontologist, 41*(5). https://academic.oup.com/gerontologist/article-abstract/41/5/652/596578

Bei, E., Rotem0Mindali, O., & Vilchinsky, N. (2020). Providing care from afar: A growing yet understudied phenomenon in the caregiving field. *Frontiers in Psychology, 11*(681). https://doi.org/10.3389/fpsyg.2020.00681

Berglund, E., Lytsy, P., & Westerling, R. (2015). Health and wellbeing in informal caregivers and non-caregivers: A comparative cross-sectional study of the Swedish general population. *Health and Quality of Life Outcomes, 13*(109). https://doi.org/10.1186/s12955-015-0309-2

Better Care Better Jobs Act, 117th Cong. (2021). https://www.aging.senate.gov/imo/media/doc/Better%20Care%20Better%20Jobs%20Act%20One%20Pager%20SBS%20072821.pdf

Biddle, B.J. (1986). Recent developments in role theory. *Annual Review of Sociology, 12,* 67-92.

Biddle, B.J. & Thomas, E.J. (Eds.). (1966). *Role theory: Concepts and research.* John Wiley & Sons, Inc.

Birdsong, M. (2020). *How we show up*. Hachette Book Group.

Birdsong, M. (Host). (2020, February 5). We all deserve an income floor: Why the bold policy of guaranteed income works (No. 4) [Audio podcast episode]. In *More Than Enough.* The Nation. https://www.thenation.com/podcast/economy/guaranteed-income-stockton/

Blair-Loy, M. & Wharton, A.S. (2002). Employees' use of work-family policies and the workplace social context. *Social Forces, 80*(3), 813 – 845.

Bockting W. O., Miner M. H., Swinburne Romine R. E., Hamilton A., Coleman E. (2013). Stigma, mental health, and resilience in an online sample of the US transgender population. *Am. J. Public Health* 103, 943–951. https://doi.org/10.2105/AJPH.2013.301241

Boesch, D. (2019). Paid family and medical leave must be comprehensive to help workers and their children. *Center for American Progress.* https://www.americanprogress.org/issues/women/reports/2019/07/16/472026/paid-family-medical-leave-must-comprehensive-help-workers-children/

Boumans, N. P. G., & Dorant, E. (2014). Double-duty caregivers: Healthcare professionals juggling employment and informal caregiving. A survey on personal health and work experiences. *Journal of Advanced Nursing, 70*(7), 1604–1615. https://doi.org/10.1111/jan.12320

Bovino, B.A. & Zafar, R. (2021, June 8). *How the advancement of Black women will build a better economy for all.* S&P Global. https://www.spglobal.com/en/research-

insights/featured/how-the-advancement-of-black-women-will-build-a-better-economy-for-all

Bozarth, K. & Hanks, A. (2020, April 9). *Structural racism is exacerbating the coronavirus pandemic for Black people – especially Black women.* Ms. Magazine. https://msmagazine.com/2020/04/09/structural-racism-is-exacerbating-the-coronavirus-pandemic-for-black-people-especially-black-women/

Bradford J., Reisner S. L., Honnold J. A., Xavier J. (2013). Experiences of transgender-related discrimination and implications for health: results from the Virginia transgender health initiative study. *Am. J. Public Health* 103, 1820–1829. 1 https://doi.org/0.2105/AJPH.2012.300796

Braun, V. & Clarke, V. (2008). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.

Breidenbach, M. (2003). *A family impact analysis of the Family and Medical Leave Act of 1993.* University of Wisconsin Center of Excellence in Family Studies. https://www.purdue.edu/hhs/hdfs/fii/wp-content/uploads/2015/06/fia_analyses_fpfmla.pdf

Brody, E. M. (2004). Women in the middle: Their parent care years (2nd ed.). Springer Publishing Company, Inc.

Brown, M. & Pitt-Catsouphes, M. (2016). A mediational model of workplace flexibility, work-family conflict, and perceived stress among caregivers of older adults. *Community, Work & Family, 19(4),* 379-395. https://doi.org/10.1080/13668803.2015.1034656

Buchanan, N.T. & Ormerod, A.J. (2002). Racialized sexual harassment in the lives of

    African American women. *Women & Therapy, 25*(3/4), 107-124.

Buildremote. (2021, November 15). *Every company announcing a hybrid work model:*

    Nov 15, 2021 update. https://buildremote.co/hybrid-work/hybrid-work-companies-

    list/

Byker, T., & Patel, E. (2021). A *proposal for a federal paid parental and medical leave*

    program. The Hamilton Project.

    https://www.hamiltonproject.org/papers/a_proposal_for_a_federal_paid_parental_a

    nd_medical_leave_program

Calderon, V., & Tennstedt, S. L. (2021). Ethnic differences in the expression of caregiver

    burden: Results of a qualitative study. *Latino Elders and the Twenty-First Century:*

    Issues and Challenges for Culturally Competent Research and Practice, *4372*, 159–

    178. https://doi.org/10.4324/9781315821382-10

Campione, J.R. & Zebrak, K.A. (2020). Predictors of unmet need among informal

    caregivers. *Journal of Gerontology: Social Sciences, 75*(10), 2181-2192.

    https://doi.org/10.1093/geronb/gbz165

Campos-Castillo, C. & Ewoodzie, K. (2014). Relational trustworthiness: How status

    affects intra-organizational inequality in job autonomy. *Social Science Research, 44*,

    60-74. https://doi.org/10.1016/j.ssresearch.2013.11.001

Caputo, J., Pavalko, E.K., & Hardy, M.A. (2016). The long-term effects of caregiving on

    women's health and mortality. *Journal of Marriage and Family, 78*, 1382-1398.

    https://doi.org/10.1111/jomf.12332

Carers UK. (2020, April). *Caring behind closed doors: Forgotten families in the coronavirus outbreak.* https://www.carersuk.org/for-professionals/policy/policy-library/caring-behind-closed-doors-report

Caring Across Generations. (2021a, June 25). *New long-term bill, Pres. Biden's support for care investments reflect HCBS popularity* [Press release]. https://caringacross.org/new-home-and-community-based-services-bill-pres-biden-renewed-support-for-care-economy-reflect-growing-momentum-for-better-jobs-for-care-workers-and-better-care-for-elders-and-people-with-disabilit/

Caring Across Generations. (2021b, October 28). *Build Back Better reconciliation framework represents historic progress for home care workers, women of color, aging adults, and people with disabilities.*[Press release]. https://caringacross.org/news/build-back-better-reconciliation-framework-represents-historic-progress-for-home-care-workers-women-of-color-aging-adults-and-people-with-disabilities/

Carlson, J. A. (2010). Avoiding traps in member checking. *The Qualitative Report*, *15*, 1102–1113. http://www.nova.edu/ssss/QR/QR15-5/carlson.pdf

Carnevale, A.P., Smith, N., & Gulish, A. (2018). *Women can't win: Despite making educational gains and pursuing high-wage majors, women still earn less than men.* Georgetown University McCourt School of Public Policy Center on Education and the Workforce. https://1gyhoq479ufd3yna29x7ubjn-wpengine.netdna-ssl.com/wp-content/uploads/Women_FR_Web.pdf

Carter, N., Bryant-Lukosius, D., Dicenso, A., Blythe, J., & Neville, A. J. (2014). The use

    of triangulation in qualitative research. *Oncology Nursing Forum*, *41*(5), 545–547.

    https://doi.org/10.1188/14.ONF.545-547

Center for a Responsible Federal Budget. (2020), March 25). *What's in the $2 trillion*

    coronavirus relief package? https://www.crfb.org/blogs/whats-2-trillion-

    coronavirus-relief-package

Centers for Disease Control and Prevention. (2021a, January 26). *How to protect yourself*

    and others [Infographic]. https://www.cdc.gov/coronavirus/2019-ncov/prevent-

    getting-sick/prevention-H.pdf

Centers for Disease Control and Prevention. (2021b, July 19). *Risk for COVID-19*

    infection, hospitalization, and death by age group.

    https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-

    discovery/hospitalization-death-by-age.html

Centers for Disease Control and Prevention. (2021c, April 19). *Health equity*

    considerations & racial & ethnic minority groups.

    https://www.cdc.gov/coronavirus/2019-ncov/community/health-equity/race-

    ethnicity.html

Centers for Disease Control and Prevention. (2021b, August 2). *COVID-19 risks and*

    vaccine information for older adults. https://www.cdc.gov/coronavirus/2019-

    ncov/need-extra-precautions/older-adults.html

Chatterjee, R. & Kwong, E. (Hosts). (2021, August 2). Caregiving during the pandemic
    takes a toll on mental health [Audio podcast episode]. In *Short Wave.* NPR.
    https://www.npr.org/transcripts/1020719900

Chesley, N. & Moen, P. (2006). When workers care: Dual-earner couples' caregiving
    strategies, benefit use, and psychological well-being. *The American Behavioral*
    Scientist, 49(9), 1248-1269. https://doi.org/10.1177/0002764206286388

Cho, S., Crenshaw, K.W., & McCall, L. (2013). Toward a field of intersectionality
    studies: Theory, applications, and praxis. *Signs: Journal of Women in Culture and*
    Society, 38(4), 785-810.

Clendon, J., & Walker, L. (2017). Nurses as family caregivers – barriers and enablers
    facing nurses caring for children, parents or both. *Journal of Nursing Management*,
    25(2), 93–101. https://doi.org/10.1111/jonm.12445

Coakley, M., Fadiran, E. O., Parrish, L. J., Griffith, R. A., Weiss, E., & Carter, C. (2012).
    Dialogues on diversifying clinical trials: Successful strategies for engaging women
    and minorities in clinical trials. *Journal of Women's Health*, *21*(7), 713-716.
    https://doi.org/10.1089/jwh.2012.3733

Cohen, C.A., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving:
    Rounding out the caregiver experience. *International Journal of Geriatric*
    Psychiatry, 17, 184-188. https://doi.org/10.10002/gps.561

Cohen, M.Z., Kahn, D.L., & Steeves, R.H. (2000). Hermeneutic phenomenological
    research: A practical guide for nurse researchers. SAGE Publications, Inc.
    https://dx.doi.org/10.4135/9781452232768

Cohen, S. A., Sabik, N. J., Cook, S. K., Azzoli, A. B., & Mendez-Luck, C. A. (2019).

    Differences within Differences: Gender Inequalities in Caregiving Intensity Vary by

    Race and Ethnicity in Informal Caregivers. *Journal of Cross-Cultural Gerontology*,

    34(3), 245–263. https://doi.org/10.1007/s10823-019-09381-9

Collins, P.H. & Bilge, S. (2016). *Intersectionality.* Polity Press.

Collinson, C. & De La Torre, H. (2017). *The many faces of caregivers: A close-up look at*

    caregiving and its impacts. TransAmerica Institute.

    https://www.transamericainstitute.org/docs/default-source/caregivers-research/race-

    ethnicity-influences-on-caregiving-2017.pdf

Conger, K. (2017). *Of mice, men and women.* Sex, Gender, and Medicine.

    https://stanmed.stanford.edu/2017spring/how-sex-and-gender-which-are-not-the-

    same-thing-influence-our-health.html#

Connley, C. (2021, February 8). Women's labor force participation rate hit a 33-year low

    in January, according to new analysis. *CNBC.*

    https://www.cnbc.com/2021/02/08/womens-labor-force-participation-rate-hit-33-

    year-low-in-january-2021.html

Coronavirus Aid, Relief, and Economic Security Act ("CARES Act"), Pub. L. No. 116-

    136, 134 Stat. 281 (2020). https://www.congress.gov/116/plaws/publ136/PLAW-

    116publ136.pdf

Corvin, J., Chan, I., Tezak, A., Carpenter, K., Loi, C.A., Gonzales, J., & Hoare, I. (2017).

    Caring for individuals with chronic illness and minor depression: Latino perceptions

of caregiver burden. *Journal of Gerontological Social Work, 60*(1), 79-95.

   https://doi.org/10.1080/01634372.2016.1268230

Covinsky, K.E., Eng, C., Lui, L., Sands, L.P., Sehgal, A.R., Walter, L.C., Wieland, D.,

   Eleazer, G.P., & Yaffe, K. (2001). Reduced employment in caregivers of frail elders:

   Impact of ethnicity, patient clinical characteristics, and caregiver characteristics.

   Journal of Gerontology: MEDICAL SCIENCES, *56A*(11), M707-713.

Crampton, S.M. & Mishra, J.M. (1995). Family and medical leave legislation:

   Organizational policies & strategies. *Public Personnel Management, 24*(3), 271-289.

Crandall, W., & Gao, L. (2005). An Update on Telecommuting: Review and Prospects

   for Emerging Issues. *S.A.M. Advanced Management Journal*, *70*(3), 30–37.

Credit for Caring Act of 2021, S.1670, 117th Cong. (2021).

   https://www.congress.gov/bill/117th-congress/senate-bill/1670/text?r=57&s=1

Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: A Black feminist

   critique of antidiscrimination doctrine, feminist theory and antiracist politics. *The*

   University of Chicago Legal Forum, 1(8), 139-167.

Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry.

   Theory into Practice, *39*(3), 124–130. https://doi.org/10.1207/s15430421tip3903_2

Creswell, J.W. (2013). *Qualitative inquiry & research design: Choosing among the five*

   approaches. Sage Publications, Inc.

Dardas, A. Z., Williams, A., Kitchen, P., & Wang, L. (2019). Assisted-transport

   caregiving and its impact towards carer-employees. *Journal of Gerontological*

   Social Work, *62*(4), 475–497. https://doi.org/10.1080/01634372.2019.1596184

Del-Pino-Casado, R., Cardosa, M. R., López-Martínez, C., & Orgeta, V. (2019). The

   association between subjective caregiver burden and depressive symptoms in carers

   of older relatives: A systematic review and meta-analysis. *PLoS ONE*, *14*(5), 1–16.

   https://doi.org/10.1371/journal.pone.0217648

Department of the Treasury. (2021, March 18). *FACT SHEET: The American Rescue*

   Plan will deliver immediate economic relief to families [Policy Brief]. Fact-Sheet-

   03-18-21.pdf (treasury.gov)

DePasquale, N., Davis, K.D., Zarit, S.H., Moen, P., Hammer, L., & Almeida, D.M.

   (2016). Combining formal and informal caregiving roles: The psychosocial

   implications of double- and triple-duty care. *Journals of Gerontology: Psychological*

   Sciences, 71(2), 201-211. https://doi.org/10.1093/geronb/gbu139

DePasquale, N., Polenick, C. A., Davis, K. D., Moen, P., Hammer, L. B., & Almeida, D.

   M. (2017). The psychosocial implications of managing work and family caregiving

   roles: Gender differences among information technology professionals. *Journal of*

   Family Issues, *38*(11), 1495–1519. https://doi.org/10.1177/0192513X15584680

DePasquale, N., Mogle, J., Zarit, S. H., Okechukwu, C., Kossek, E. E., & Almeida, D. M.

   (2018a). The family time squeeze: Perceived family time adequacy buffers work

   strain in certified nursing assistants with multiple caregiving roles. *Gerontologist*,

   58(3), 546–555. https://doi.org/10.1093/geront/gnw191

DePasquale, N., Polenick, C., Davis, K., & Berkman, L. (2018b). A bright side to the

   work-family interface: Husbands' support as a resource in double-and-triple-duty

   caregiving wives' work lives. *Gerontologist, 57*(5), 1010.

DePasquale, N., Sliwinski, M. J., Zarit, S. H., Buxton, O. M., & Almeida, D. M. (2019). Unpaid caregiving roles and sleep among women working in nursing homes: A longitudinal study. *Gerontologist*, *59*(3), 474–485. https://doi.org/10.1093/geront/gnx185

Dettling, L.J., Hsu, J.W., Jacobs, L., Moore, K.B., & Thompson, J.P. (2017). *Recent trends in wealth-holding by race and ethnicity: Evidence from the survey of consumer finances.* Board of Governors of the Federal Research System. https://www.federalreserve.gov/econres/notes/feds-notes/recent-trends-in-wealth-holding-by-race-and-ethnicity-evidence-from-the-survey-of-consumer-finances-20170927.htm

Dilworth-Anderson, P., Williams, I. C., & Gibson, B. E. (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980-2000). *Gerontologist*, *42*(2), 237–272. https://doi.org/10.1093/geront/42.2.237

Do, Y.K., Norton, E.C., Stearns, S.C., & Van Houtven, C.H. (2015). Informal care and caregiver's health. *Health Economics, 24*, 224-237. https://doi.org/10.1002/hec.3012

Donovan, S.A. (2019). *Paid family leave in the United States* (R44835). Congressional Research Service. https://fas.org/sgp/crs/misc/R44835.pdf

Douglas, S.L., Mazanec, P., Lipson, A., & Leuchtag, M. (2016). Distance caregiving a family member with cancer: A review of the literature on distance caregiving and recommendations for future research. *World Journal of Clinical Oncology, 7*(2), 214-219. https://doi.org/10.5306/wjco.v7.i2.214

Duxbury, L., Higgins, C., & Smart, R. (2011). Elder care and the impact of caregiver strain on the health of employed caregivers. *Work, 40*(1), 29-40. https://doi.org/10.3233/WOR-2011-1204

Eagly, A.H. & Karau, S.J. (2002). Role congruity theory of prejudice toward female leaders. *Psychological Review, 109*(3), 573-598. https://doi.org/10.1037//0033-295X.109.3.573

Earle, A. & Heymann, J. (2011). Protecting the health of employees caring for family members with special health care needs. *Social Science & Medicine, 73,* 68-78.

Easterling, K. (2021, October 1). *What is the Better Care Better Jobs Act?* HomeCare. https://www.homecaremag.com/october-2021/what-is-better-care-better-jobs-act

Escobari, M., Seyal, I., & Daboin, C. (2020, November 16). *New but narrow job pathways for America's unemployed and low-wage workers.* The Brookings Institution. https://www.brookings.edu/blog/up-front/2020/11/16/new-but-narrow-job-pathways-for-americas-unemployed-and-low-wage-workers/

Ewing-Nelson, C. (2021, February). *Another 275,000 women left the labor force in January.* National Women's Law Center. https://nwlc.org/wp-content/uploads/2021/02/January-Jobs-Day-FS.pdf

Fabius, C., Wolff, J.L., & Kasper, J.D. (2020). Race differences in characters and experiences of Black and white caregivers of older Americans. *Gerontologist, XX*(XX), 1-10. https://doi.org/10.1093/geront/gnaa042

Families First Coronavirus Response Act, Pub. L. No. 116-127, 134 Stat. 178 (2020). https://www.congress.gov/116/plaws/publ127/PLAW-116publ127.pdf

Family caregiving issues and the National Family Caregiver Support Program. U.S. Senate Special Committee on Aging, 112th Cong. (2011) (written testimony of former First Lady Rosalynn Carter). https://www.cartercenter.org/news/editorials_speeches/rosalynn-carter-committee-on-aging-testimony.html

Feinberg, L. F. (2018). *Breaking new ground: Supporting employed family caregivers with workplace leave policies.* AARP Public Policy Institute. https://www.aarp.org/content/dam/aarp/ppi/2018/08/breaking-new-ground-supporting-employed-family-caregivers-with-workplace-leave-policies.pdf

Fine, T.S. (2006). The Family and Medical Leave law: Feminist social policy? Journal of Policy Practice, 5(1), 49-66. https://doi.org/10.1300/J508v05n01_04

Fitzhugh, E., Florant, A., Julien, J., Noel, N., Pinder, D., Stewart, S., Wright, J., & Yamoah, S. (2020, April). *COVID-19: Investing in Black lives and livelihoods.* McKinsey & Company. https://www.mckinsey.com/industries/public-and-social-sector/our-insights/covid-19-investing-in-black-lives-and-livelihoods#

French, K.A., Dumani, S., Allen, T.D., & Shockley, K.M. (2018). A meta-analysis of work-family conflict and social support. *Psychological Bulletin, 144*(3), 284-314. https://doi.org/10.1037/bu10000120

Frey, W.H. (2020, July). *The nation is diversifying even faster than predicted, according to new census data.* The Brookings Institution. https://www.brookings.edu/research/new-census-data-shows-the-nation-is-diversifying-even-faster-than-predicted/

Fuller, J.B. & Raman, M. (2019). *The caring company: How employers can cut costs and boost productivity by helping employees manage caregiving needs*. Harvard Business School. https:// www.hbs.edu/managing-the-future-of-work/research/Pages/the-caring-company.aspx

Gajendran, R. S., & Harrison, D. A. (2007). The good, the bad, and the unknown about telecommuting: meta-analysis of psychological mediators and individual consequences. *Journal of Applied Psychology*, *92*(6), 1524–1541. https://doi.org/10.1037/0021-9010.92.6.1524

Galanti, T., Guidetti, G., Mazzei, E., Zappalà, S., & Toscano, F. (2021). Work from home during the COVID-19 outbreak: The impact on employees' remote work productivity, engagement, and stress. *Journal of Occupational and Environmental Medicine*, *63*(7), E426–E432. https://doi.org/10.1097/JOM.0000000000002236

Gentles, S. J., Charles, C., Ploeg, J., & McKibbon, K. (2015). Sampling in qualitative research: Insights from an overview of the methods literature. *Qualitative Report*, *20*(11), 1772–1789. https://doi.org/10.46743/2160-3715/2015.2373

Genworth. (2020). *Consumer sentiment survey*. https://www.genworth.com/about-us/covid-19/consumer-survey.html

Genworth. (2021). *Costs of care trends and insights.* https://www.genworth.com/aging-and-you/finances/cost-of-care/cost-of-care-trends-and-insights.html

George, L.K. & Gwyther, L.P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *The Gerontologist, 26*(3), 253-259.

George, S., Duran, N., & Norris, K. (2014). A systematic review of barriers and

    facilitators to minority research participation among African Americans, Latinos,

    Asian Americans, and Pacific Islanders. *American Journal of Public Health*, *104*(2),

    16–31. https://doi.org/10.2105/AJPH.2013.301706

Giebel, C., Lord, K., Cooper, C., Shenton, J., Cannon, J., Pulford, D., Shaw, L., Gaughan,

    A., Tetlow, H., Butchard, S., Limbert, S., Callaghan, S., Whittington, R., Rogers, C.,

    Komuravelli, A., Rajagopal, M., Eley, R., Watkins, C., Downs, M., … Gabbay, M.

    (2021a). A UK survey of COVID-19 related social support closures and their effects

    on older people, people with dementia, and carers. *International Journal of*

    Geriatric Psychiatry, *36*(3), 393–402. https://doi.org/10.1002/gps.5434

Giebel, C., Cannon, J., Hanna, K., Butchard, S., Eley, R., Gaughan, A., Komuravelli, A.,

    Shenton, J., Callaghan, S., Tetlow, H., Limbert, S., Whittington, R., Rogers, C.,

    Rajagopal, M., Ward, K., Shaw, L., Corcoran, R., Bennett, K., & Gabbay, M.

    (2021b). Impact of COVID-19 related social support service closures on people with

    dementia and unpaid carers: A qualitative study. *Aging and Mental Health*, *25*(7),

    1281–1288. https://doi.org/10.1080/13607863.2020.1822292

Gitis, B. (2021, May 15). *Morning consult poll: Caregiving led adults out of the*

    workforce during COVID-19 and paid family leave can help bring them back.

    Bipartisan Policy Center. https://bipartisanpolicy.org/blog/caregiving-covid-

    factsheet/

Glynn, S.J., Boushey, H., & Berg, P. (2016). *Who gets time off? Predicting access to paid*

    leave and workplace flexibility. Center for American Progress.

https://www.americanprogress.org/issues/economy/reports/2016/04/26/134824/who-gets-time-off/

Goode, W.J. (1960). A theory of role strain. *American Sociological Review, 25*(4), 483-496.

Goodman, J. M., & Schneider, D. (2021). *The association of paid medical and caregiving leave with the economic security and wellbeing of service sector workers. BMC Public Health, 21*(1969). 1–8. https://doi.org/10.1186/s12889-021-11999-9

Gould, E. & Kassa, M. (2021). *Low-wage, low-hours workers were hit hardest in the COVID-19 recession: The State of Working America 2020 employment report.* Economic Policy Institute. https://www.epi.org/publication/swa-2020-employment-report/

Graham, J. (2021, April 9). What's in Biden's $400 billion plan to support families' long-term health needs. *NPR*. https://www.npr.org/sections/health-shots/2021/04/09/985567929/whats-in-bidens-400-billion-plan-to-support-families-long-term-health-needs

Greenfield, J.C., Hasche, L., Bell, L.M., & Johnson, H. (2018). Exploring how workplace and social policies relate to caregivers' financial strain. *Journal of Gerontological Social Work 61*(8), 849-866. https://doi.org/10.1080/01634372.2018.1487895

Greenhaus, J.H. & Beutell, N.J. (1985). Sources of conflict between work and family roles. *The Academy of Management Review, 10*(1), 76-88.

Greenhaus, J.H., Ziegert, J.C., & Allen, T.D. (2011). When family-supportive supervision

    matters: Relations between multiple sources of support and work-family balance.

    Journal of Vocational Behavior, 80(2), 266-275.

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough?: An

    experiment with data saturation and variability. *Field Methods*, *18*(1), 59–82.

    https://doi.org/10.1177/1525822X05279903

Gupta, R. (2000). A path model of elder caregiver burden in Indian/Pakistani families in

    the United States. *International Journal of Aging and Human Development*, *51*(4),

    295–313. https://doi.org/10.2190/J9XY-V3E0-NP1B-UNA5

Hamilton, R. J., & Bowers, B. J. (2006). Internet recruitment and e-mail interviews in

    qualitative studies. *Qualitative Health Research*, *16*(6), 821–835.

    https://doi.org/10.1177/1049732306287599

Harry, B., Sturges, K.M., & Klingner, J.K. (2005). Mapping the process: An exemplar of

    process and challenge in grounded theory analysis. *Educational Researcher, 34*(2),

    3-13.

Hash, K., & Mankowski, M. (2017). Caregiving in the LGBT community. *Annual Review*

    of Gerontology & Geriatrics, 37(1), 77-IX.

Health Service Executive. (2021, May 7). *People at higher risk from COVID-19.*

    https://www2.hse.ie/conditions/covid19/people-at-higher-risk/overview

Hegewisch, A. & Mefferd, E. (2021, June). *A slow climb back from the "she-cession":*

    High jobs deficit in child care and school sectors continues [Quick Figure #Q096].

Institute for Women's Policy Research. https://iwpr.org/wp-content/uploads/2021/06/QF_Slow-Climb-Back_Jobs-Data-May-2021_FINAL.pdf

Henle, C. A., Fisher, G. G., McCarthy, J., Prince, M. A., Mattingly, V. P., & Clancy, R. L. (2020). Eldercare and childcare: How does caregiving responsibility affect job discrimination? *Journal of Business and Psychology*, *35*(1), 59–83. https://doi.org/10.1007/s10869-019-09618-x

Heymann, J. & El-Dardiry, G. (2008). Work and family policy in the United States: Past gaps, future possibilities. *International Journal, 64*(1), 125-133.

Heymann, J., Sprague, A., Earle, A., McCormack, M., Waisath, W., & Raub, A. (2021). *U.S. sick leave in global context: U.S. eligibility rules widens inequalities despite readily available solutions.* Health Affairs. https://doi.org/10.1377/hlthaff.2021.00731

Hill, H.D. (2013). Paid sick leave and job stability. *Work Occup., 40*(2). https://doi.org/10.1177/0730888413480893

Hokke, S., Bennetts, S. K., Crawford, S., Leach, L., Hackworth, N. J., Strazdins, L., Nguyen, C., Nicholson, J. M., & Cooklin, A. R. (2021). Does flexible work 'work' in Australia? A survey of employed mothers' and fathers' work, family and health. *Community, Work and Family*, *24*(4), 488–506. https://doi.org/10.1080/13668803.2019.1704397

Hoobler, J.M., Wayne, S.J., & Lemmon, G. (2009). Bosses' perceptions of family-work conflict and women's promotability: Glass ceiling effects. *Academy of Management Journal, 52*(5), 939-957.

Hopps, M., Iadeluca, L., McDonald, M., & Makinson, G. T. (2017). The burden of family

    caregiving in the United States: Work productivity, health care resource utilization,

    and mental health among employed adults. *Journal of Multidisciplinary Healthcare*,

    10, 437–444. https://doi.org/10.2147/JMDH.S135372

Horsley, S. (2020a). *Women now outnumber men on U.S. payrolls*. NPR.

    https://www.npr.org/2020/01/10/795293539/women-now-outnumber-men-on-u-s-

    payrolls

Horsley, S. (2020b). *Women are losing more jobs in coronavirus shutdowns*. NPR.

    https://www.npr.org/2020/04/08/829141182/women-are-losing-more-jobs-in-

    coronavirus-shutdowns

Houghton, C., Casey, D., Shaw, D., & Murphy, K. (2013). Rigour in qualitative case-

    study research. *Nurse Researcher, 20*(4), 12-17.

Hughes, S.L., Giobbie-Hurder, A., Weaver, F.M., Kubal, J.D., & Henderson, W. (1999).

    Relationship between caregiver burden and health-related quality of life. *The*

    Gerontologist, 39(5). 534-545.

Hutzler, A. (2021, June 29). 163.5 million stimulus checks totaling $390B have been sent

    through American Rescue Plan. *Newsweek.* https://www.newsweek.com/1635-

    million-stimulus-checks-totaling-390b-have-been-sent-through-american-rescue-

    plan-1605292

IMPAQ International & The Institute for Women's Policy Research. (2017). *The effects*

    of FMLA and awareness on family leave-taking (Issue brief).

https://www.dol.gov/sites/dolgov/files/OASP/legacy/files/IMPAQ-Eligibility-and-Awareness.pdf

Institute for Women's Policy Research. (2018, February). *Paid family and medical leave insurance: Modest costs are a good investment for America's economy* (IWPR #B368). https://iwpr.org/wp-content/uploads/2018/02/B368_Paid-Leave-Fact-Sheet-1.pdf

Irani, E., Niyomyart, A., & Zauszniewski, J. A. (2021). Caregiving stress and self-rated health during the COVID-19 pandemic: The mediating role of resourcefulness. *Issues in Mental Health Nursing*, *42*(11), 982–988. https://doi.org/10.1080/01612840.2021.1924324

Irish, A. M., White, J. S., Modrek, S., & Hamad, R. (2021). Paid family leave and mental health in the U.S.: A quasi-experimental study of state policies. *American Journal of Preventive Medicine*, *61*(2), 182–191. https://doi.org/10.1016/j.amepre.2021.03.018

Janevic, M.R. & Connell, C.M. (2001). Racial, ethnic, and cultural differences in the dementia caregiving experiences: Recent findings. *The Gerontologist, 41*(3), 334-347.

Jelliffe, E., Pangburn, P., Pichler, S., & Ziebarth, N.R. (2021). Awareness and use of (emergency) sick leave: US employees' unaddressed sick leave needs in a global pandemic. *PNAS, 118*(29). https://doi.org/10.1073/pnas.2107670118

Jenkins, R. (2014). *Social identity*. Taylor & Francis Group.

Johns Hopkins University. (2021, November). COVID-19 Dashboard by the Center for

    Systems Science and Engineering at Johns Hopkins University.

    https://coronavirus.jhu.edu/map.html

Johnson, R.W. & Lo Sasso, A.T. (2006). The impact of elder care on women's labor

    supply. *Inquiry, 43*, 195-210. https://doi.org/10.5034/inquiryjrnl_43.3.195

Joshi, P., Baldiga, M., & Huber, R. (2020, January 16). *Unequal access to FMLA leave*

    persists. Diversity Data Kids. http://diversitydatakids.org/research-library/data-

    visualization/unequal-access-fmla-leave-persists

Joshi, P., Baldiga, M., Earle, A., Huber, R., Osypuk, T., & Acevedo-Garcia, D. (2021).

    How much would family and medical leave cost workers in the US? Racial/ethnic

    variation in economic hardship under unpaid and paid policies. *Community, Work*

    and Family, *24*(5), 517–540. https://doi.org/10.1080/13668803.2019.1704398

Juratovac, E. & Zauszniewski, J.A. (2014). Full-time employed and a family caregiver: A

    profile of women's workload, effort, and health. *Women's Health Issues, 24*(2)*,*

    187-196.

Kaiser Family Foundation. (2021, July 15). *Health coverage of immigrants.*

    https://www.kff.org/racial-equity-and-health-policy/fact-sheet/health-coverage-of-

    immigrants/

Kallio, H., Pietilä, A. M., Johnson, M., & Kangasniemi, M. (2016). Systematic

    methodological review: developing a framework for a qualitative semi-structured

    interview guide. *Journal of Advanced Nursing*, *72*(12), 2954–2965.

    https://doi.org/10.1111/jan.13031

Kaplan, G., Moll B., & Violante, G.L. (2020, August). The great lockdown and the big

    stimulus: Tracing the pandemic possibility frontier for the U.S. (Working Paper No.

    2020-119). https://bfi.uchicago.edu/wp-

    content/uploads/BFI_RB_Kaplan_082720v3.pdf

Karkee, V. (2021, March 29). *How women are being left behind in the quest for decent*

    work for all. International Labour Organization. https://ilostat.ilo.org/how-women-

    are-being-left-behind-in-the-quest-for-decent-work-for-all/

Kashen, J., Glynn, S.J., & Novello, A. (2020, October). *How COVID-19 sent women's*

    workforce progress backward. Center for American Progress.

    https://www.americanprogress.org/issues/women/reports/2020/10/30/492582/covid-

    19-sent-womens-workforce-progress-

    backward/#:~:text=OVERVIEW,gender%20equity%20back%20a%20generation.

Kayaalp, A., Page, K.J., & Rospenda, K.M. (2020). Caregiver burden, work-family

    conflict, family-work conflict, and mental health of caregivers: A mediational

    longitudinal study. *Work & Stress.* https://doi.org/10.1080/02678373.2020.1832609

Kerr, N. (2021, July 15). *Credit for Caring Act would provide tax credit to family*

    caregivers. AARP. https://www.aarp.org/caregiving/financial-legal/info-2021/new-

    credit-for-caring-act.html

Klerman, J.A., Daley, K. & Pozniak, A. (2012). *Family and medical leave in 2012:*

    Executive summary. Abt Associates, U.S. Department of Labor.

    https://www.dol.gov/sites/dolgov/files/OASP/legacy/files/FMLA-2012-Executive-

    Summary.pdf

Knight, B. G., & Sayegh, P. (2010). Cultural values and caregiving: The updated

sociocultural stress and coping model. *Journals of Gerontology - Series B

Psychological Sciences and Social Sciences*, *65 B*(1), 5–13.

https://doi.org/10.1093/geronb/gbp096

Kochhar, R. (2020). *Hispanic women, immigrants, young adults, those with less

education hit hardest by COVID-19 job losses.* Pew Research Center.

https://www.pewresearch.org/fact-tank/2020/06/09/Hispanic-women-immigrants-

young-adults-those-with-less-education-hit-hardest-by-covid-19-job-losses/

Kodner, D.L. (2003). Consumer-directed services: Lessons and implications for

integrated systems of care. *International Journal of Integrated Care, 3.*

https://doi.org/10.5334/ijic.80

Kossek, E.E. & Lautsch, B.A. (2017). Work-life flexibility for whom? Occupational

status and work-life inequality in upper, middle, and lower level jobs. *Academy of

Management Annals, 12*(1). https://doi.org/10.5465/annals.2016.0059

Kossek, E.E., Lautsch, B.A., & Eaton, S.C. (2006). Telecommuting, control, and

boundary management: Correlates of policy use and practice, job control, and

work-family effectiveness. *Journal of Vocational Behavior, 68*, 347-367.

https://doi.org/10.1016/j.jvb.2005.07.002

Kossek, E. E., & Lee, K. H. (2020). The coronavirus & work–life inequality: Three

evidence-based initiatives to update U.S. work–life employment policies.

Behavioral Science and Policy, *6*(2), 77–85. https://doi.org/10.1353/BSP.2020.0018

Lacey, R.E., McMunn, A., & Webb, E., (2018). Informal caregiving and markers of adiposity in the UK Household Longitudinal Study. *PLoS ONE*, *13*(7). https://doi.org/10.1371/journal.pone.0200777

Lahaie, C., Earle, A., & Heymann, J. (2013). An Uneven Burden: Social Disparities in Adult Caregiving Responsibilities, Working Conditions, and Caregiver Outcomes. *Research on Aging*, *35*(3), 243–274. https://doi.org/10.1177/0164027512446028

LeanIn.Org & SurveyMonkey. (2020). *Impact of COVID-19 on women.* https://docs.google.com/document/d/19UkIM_LtTUj02El9Hw7U03-ybv0sCGUNTYGdnrHz7FU/edit

Leggett, A. N., Carmichael, A., Leonard, N., Jackson, J., Kirch, M., Solway, E., Kullgren, J. T., Singer, D., Malani, P. N., & Gonzalez, R. (2021). Care challenges due to COVID-19 and mental health among caregivers of U.S. adults with a chronic or disabling condition. *Innovation in Aging*, *5*(3), 1–10. https://doi.org/10.1093/geroni/igab031

Li, A., Shaffer, J., & Bagger, J. (2015). The psychological well-being of disability caregivers: Examining the roles of family strain, family-to-work conflict, and perceived supervisor support. *Journal of Occupational Health Psychology, 20*(1), 40-49. https://doi.org/10.1037/a0037878

Li, L. & Lee, Y. (2019). Employment adjustment and mental health of employed family caregivers in Canada. *Aging & Mental Health*. https://doi.org/10.1080/13607863.2019.1647136

Lightfoot, E., Moone, R., Suleiman, K., Otis, J., Yun, H., Kutzler, C., & Turck, K.

(2021). Concerns of family caregivers during covid-19: The concerns of caregivers

and the surprising silver linings. *Journal of Gerontological Social Work*, *64*(6), 656–

675. https://doi.org/10.1080/01634372.2021.1898512

Linneberg, M.S., & Korsgaard, S. (2019). Coding qualitative data: a synthesis guiding the

novice. *Qualitative Research Journal*, *19*(3), 259–270. https://doi.org/10.1108/QRJ-

12-2018-0012

Lobosco, K. & Luhby, T. (2021, November 25). Here's what's in the bipartisan

infrastructure package. *CNN*.

https://www.cnn.com/2021/07/28/politics/infrastructure-bill-explained/index.html

Lunnay, B., Borlagdan, J., McNaughton, D., & Ward, P. (2015). Ethical use of social

media to facilitate qualitative research. *Qualitative Health Research*, *25*(1), 99–109.

https://doi.org/10.1177/1049732314549031

Lutz, W. (2021, October). *Jobs report shows first decline in payroll employment for

women since December 2020.* Institute for Women's Policy Research.

https://iwpr.org/media/press-releases/jobs-report-shows-first-decline-in-payroll-

employment-for-women-since-december-2020/

Lykens, K., Moayad, N., Biswas, S., Reyes-Ortiz, C., & Singh, K.P. (2014). Impact of a

community based implementation of REACH II program for caregivers of

Alzheimer's patients. *PLOS ONE, 9*(2), 1-7.

Makin, C. (2019, January 23). 'It's just something you do,' some caregivers do not self-

identify. *My Central Jersey*.

https://www.mycentraljersey.com/story/news/local/outreach/caring-communities/2019/01/23/caregivers-self-identity-role/2513762002/

Marks, M. (1997). Party politics and family policy: The case of the Family and Medical Leave Act. *Journal of Family Issues, 18*(2), 55-70.

Marks, S.R. (1977). Multiple roles and role strain: Some notes on human energy, time and commitment. *American Sociological Review, 42*(6), 921-936.

Markus, H., & Kitayama, S. (1991). Culture and the self: Implications for cognition, emotion, and motivation. American Psychological Association. *Psychological Review*, *98*(2), 224–253.

http://web.b.ebscohost.com.libezproxy.open.ac.uk/ehost/pdfviewer/pdfviewer?vid=1&sid=620938ca-e7f2-44a8-8575-fff36c02dead%40pdc-v-sessmgr02

Martin, C.D. (2000). More than work: Race and gender differences in caregiving burden. *Journal of Family Issues, 21*(8), 986-1005.

Mascaro, L. (2021, August 10). Big win for $1T infrastructure bill: Dems, GOP come together. *Associated Press*. https://apnews.com/article/senate-infrastructure-bill-politics-joe-biden-a431f8c9f3f113b661cb3526512fc4e0

Masi, D.A. (2011). Definition and history of employee assistance programs. *UMB Digital Archive*.

https://archive.hshsl.umaryland.edu/bitstream/handle/10713/3360/Definition%20and%20History%20of%20Employee%20Assistance%20Programs%20.pdf?sequence=1&isAllowed=y#:~:text=EAPs%20in%20general%20are%20worksite,%E2%80%9D%20(Masi%2C%202000)

Matthews, R.A., Barnes-Farrell, J., & Bulger, C.A. (2010). Advancing measurement of

    work-family boundary characteristics. *Journal of Vocational Behavior, 77*, 447-460.

    https://doi.org/10.1016/j.jvb.2010.05.008

McCall, L. (2005). The complexity of intersectionality. *Signs: Journal of Women in*

    Culture and Society, 30(3), 1771-1800.

McKinsey & Company. (2019). *Women in the workplace - 2019.*

    https://www.mckinsey.com/featured-insights/gender-equality/women-in-the-

    workplace-2019

McKinsey & Company. (2020, April 14). *COVID-19: Investing in black lives and*

    livelihoods. https://www.mckinsey.com/industries/public-and-social-sector/our-

    insights/covid-19-investing-in-black-lives-and-livelihoods#

Mendez-Luck, C.A., Anthony, K.P., & Guerrero, L.R. (2020). Burden and bad days

    among Mexican-origin women caregivers. *Journals of Gerontology: Social*

    Sciences, 75(8), 1719-1730. https://doi.org/10.1093/geronb/gbz102

MetLife Mature Market Institute. (2011). *The MetLife study of caregiving costs to*

    working caregivers: Double jeopardy for baby boomers caring for their parents.

    https://www.metlife.com/assets/cao/mmi/publications/studies/2011/Highlights/mmi-

    caregiving-costs-working-caregivers-highlights.pdf

Metropolitan Policy Program at Brookings. (2019). *53 million U.S. workers are making*

    low wages, despite low national unemployment. The Brookings Institution.

    https://www.brookings.edu/wp-content/uploads/2019/11/201911_Brookings-

    Metro_Pressrelease_lowwageworkforce.pdf

Miller, C.C. (2021, May 21). The pandemic created a child-care crisis. Mothers bore the

    burden. *The New York Times.*

    https://www.nytimes.com/interactive/2021/05/17/upshot/women-workforce-

    employment-covid.html

Miyawaki, C. E. (2016). Caregiving practice patterns of Asian, Hispanic, and non-

    Hispanic white American family caregivers of older adults across generations.

    Journal of Cross-Cultural Gerontology, *31*(1), 35–55.

    https://doi.org/10.1007/s10823-016-9281-5

Mochari-Greenberger, H. & Mosca, L. (2012). Caregiver burden and nonachievement of

    healthy lifestyle behaviors among family caregivers of cardiovascular disease

    patients. *American Journal of Health Promotion, 27*(2), 84-89.

Moon, H., Haley, W.E., Rote, S.M., & Sears, J.S. (2020). Caregiver well-being and

    burden: Variations by race/ethnicity and care recipient nativity status. *Innovation in*

    Aging, 4(6). https://doi.org/10.1093/geroni/igaa045

Mortensen, J., Dich, N., Lange, T., Ramlau-Hansen, C. H., Head, J., Kivimäki, M.,

    Madsen, I.E.H., Rugulies, R., Vahtera, J., Zins, M., & Rod, N. H. (2018). Weekly

    hours of informal caregiving and paid work, and the risk of cardiovascular disease.

    European Journal of Public Health, *28*(4), 743–747.

    https://doi.org/10.1093/eurpub/ckx227

Mosquera, I., Vergara, I., Larranaga,I., Machon, M., del Rio, M., & Calderon, C. (2016).

    Measuring the impact of informal elderly caregiving: A systematic review of tools.

Quality of Life Research, 25(5), 1059-1092. https://doi.org/10.1007/s11136-015-1159-4

Moss-Kanter, R. (1975). Women and the structure of organizations: Explorations in theory and behavior. *Sociological Inquiry, 45*(2-3), 34-74. https://doi.org/10.1111/j.1475-682X.1975.tb00331.x

Mullen, C. (2021, April 12). *Women's mental, financial well-being have suffered more than men's during pandemic, study finds.* Bizwomen. https://www.bizjournals.com/bizwomen/news/latest-news/2021/04/pandemic-women-finances.html

Namkung, E.H., Greenberg, J.S., & Mailick, M.R. (2017). Well-being of sibling caregivers: Effects of kinship relationship and race. *The Gerontologist, 57*(4), 626-636. https://doi.org/10.1093/geront/gmw008

National Academies of Sciences, Engineering, and M. (2021). Short-term strategies for addressing the impacts of the covid-19 pandemic on women's workforce participation. https://doi.org/10.17226/26303

National Alliance for Caregiving & AARP. (2020). *Caregiving in the U.S.* https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf

National Institutes of Health. (2016). *Sex and gender: How being male or female can affect your health.* https://newsinhealth.nih.gov/sites/nihNIH/files/2016/May/NIHNiHMay2016.pdf

National Partnership for Women & Families. (2020, November). *Voters show bipartisan*

    support for permanent paid sick days and paid family and medical leave.

    https://www.nationalpartnership.org/our-work/resources/economic-justice/voters-

    show-bipartisan-support-for-permanent-paid-sick-days-and-paid-family-and-

    medical-leave.pdf

National Partnership for Women & Families. (2021, March). *Quantifying America's*

    gender wage gap by race/ethnicity. https://www.nationalpartnership.org/our-

    work/resources/economic-justice/fair-pay/quantifying-americas-gender-wage-

    gap.pdf

Navaie-Waliser, M.; Feldman, P.H.; Gould, D.A.; Levine, C.; Kuerbis, A.N., & Donelan,

    K. (2001). The experiences and challenges of informal caregivers: Common themes

    and differences among Whites, Blacks, and Hispanics. *The Gerontologist, 41*(6),

    733-741.

Noguchi, Y. (2021, September 29). *Obesity rates rise during pandemic, fueled by stress,*

    job loss, sedentary lifestyle. NPR. https://www.npr.org/sections/health-

    shots/2021/09/29/1041515129/obesity-rates-rise-during-pandemic-fueled-by-stress-

    job-loss-sedentary-lifestyle

Otado, J., Kwagyan, J., Edwards, D., Ukaegbu, A., Rockcliffe, F., & Osafo, N. (2015).

    Culturally Competent Strategies for Recruitment and Retention of African American

    Populations into Clinical Trials. *Clinical and Translational Science*, *8*(5), 460–466.

    https://doi.org/10.1111/cts.12285

Padgett, D.K. (2012). *Qualitative and mixed methods in public health.* SAGE

    Publications, Inc.

Padilla, M. (2021, April 2). Half a million women entered the workforce in March. *The*

    19th*. https://19thnews.org/2021/04/women-entering-workforce-march/

Park, S. S. (2021). Caregivers' Mental Health and Somatic Symptoms during COVID-19.

    Journals of Gerontology - Series B Psychological Sciences and Social Sciences,

    76(4), E235–E240. https://doi.org/10.1093/geronb/gbaa121

Parsons, T. (1951). Role conflict and the genesis of deviance. In Biddle, B.J. & Thomas,

    E.J. (Eds.), *Role theory: Concepts and research.* (pp. 275-276). John Wiley & Sons,

    Inc.

Pavalko, E.K. & Henderson, K.A. (2006). Combining care work and paid work: Do

    workplace policies make a difference? *Research on Aging*, *28(3)*, 359-374.

Paycheck Protection Program and Health Care Enhancement Act, Public L. No. 116-139,

    134 Stat. 620 (2020). https://www.congress.gov/116/plaws/publ139/PLAW-

    116publ139.pdf

Pei, X., Luo, H., Lin, Z., Keating, N., & Fast, J. (2017). The impact of eldercare on adult

    children's health and employment in transitional China. *Journal of Cross-Cultural*

    Gerontology, *32*(3), 357–372. https://doi.org/10.1007/s10823-017-9330-8

Pena-Longobardo, L.M., Del Rio-Lozano, M., Oliva-Moreno, J., Larranag-Padilla, I., &

    del Mar Garcia-Calvente, M. (2021). Health, work, and social problems in Spanish

    informal caregivers: Does gender matter? (The CUIDAR-SE Study). *International*

Journal of Environmental Research and Public Health, 18.

https://doi.org/10.3390/ijerph18147332

Petersen, A.H. (2021, August 26). The staggering, exhausting invisible costs of caring for

America's elderly. *Vox.* https://www.vox.com/the-goods/22639674/elder-care-

family-costs-nursing-home-health-care

Pew Research Center. (2016). *Changes in the American workplace.*

https://www.pewresearch.org/social-trends/2016/10/06/1-changes-in-the-american-

workplace/

Pharr, J. R., Dodge Francis, C., Terry, C., & Clark, M. C. (2014). Culture, caregiving,

and health: Exploring the influence of culture on family caregiver experiences. *ISRN*

Public Health, *2014*, 1–8. https://doi.org/10.1155/2014/689826

Phillips, D., Paul, G., Fahy, M., Dowling-Hetherington, L., Kroll, T., Moloney, B.,

Duffy, C., Fealy, G., & Lafferty, A. (2020). The invisible workforce during the

COVID-19 pandemic: Family carers at the frontline. *HRB Open Research,*

3(24). https://doi.org/10.12688/hrbopenres.13059.1

Pichler, S., Wen, K, & Ziebarth, N.R. (2020). COVID-19 emergency sick leave has

helped flatten the curve in the United States. *Health Affairs, 39*(12), 2197-2204.

https://doi.org/10.1377/hlthaff.2020.00863

Pimentel, E. (2020). COVID-19 could have a lasting, positive impact on workplace

culture. *The Conversation*, 1–7. https://theconversation.com/covid-19-could-have-a-

lasting-positive-impact-on-workplace-culture-143297

Pinquart, M. & Sorenson, S. (2003). Differences between caregivers and noncaregivers in

    psychological health and physical health: A meta-analysis. *Psychology and Aging,*

    18(2), 250-267. https://doi.org/10.1037/0882-7974.18.2.250

Pinquart, M. & Sorenson, S. (2005). Ethnic differences in stressors, resources, and

    psychological outcomes in family caregiving: A meta-analysis. *The Gerontologist,*

    45(1), 90-106.

Pinquart, M. & Sorenson, S. (2006). Gender differences in caregiver stressors, social

    resources, and health: An updated meta-analysis. *Journals of Gerontology:*

    PSYCHOLOGICAL SCIENCES, 61BI(1), P33-P45.

Pinquart, M. & Sorenson, S. (2007). Correlates of physical health of informal caregivers:

    A meta-analysis. *Journal of Gerontology: PSYCHOLOGICAL SCIENCES, 62B*(2),

    P126-137.

Pleck, J.H., Staines, G.L., & Lang, L. (1980). Conflicts between work and family life.

    Monthly Labor Review, 103(3), 29-32.

Poo, A. & Rocketto, J.M. (2021, March 31). *President Biden's jobs plans reflects critical*

    role care workers play in rebuilding U.S. economy [Press release]. Caring Across

    Generations. https://caringacross.org/press-release-president-bidens-jobs-plan-

    reflects-critical-role-care-workers-play-in-rebuilding-u-s-economy/

Population Reference Bureau. (2000, June). *American diversity and growth: Signposts*

    for the 21st century.

    https://www.prb.org/americasdiversityandgrowthsignpostsforthe21stcenturypdf503

    kb/

Porter, N.B. (2014). Finding a fix for the FMLA: A new perspective, a new solution. *Hofstra Labor & Employment Law Journal, 31*(2), 1-40.

Powell, G.N. & Butterfield, D.A. (1979). The "good manager": Masculine or androgynous? *The Academy of Management Journal, 22*(2), 395-403.

Prohaska, A., & Zipp, J. F. (2011). Gender inequality and the Family and Medical Leave Act. *Journal of Family Issues*, *32*(11), 1425–1448. https://doi.org/10.1177/0192513X11403280

Qureshi, Z. (2020). *Tackling the inequality pandemic: Is there a cure?* The Brookings Institution. https://www.brookings.edu/research/tackling-the-inequality-pandemic-is-there-a-cure/

RAISE Family Caregiving Advisory Council. (2021). *Recognize, Assist, Include, Support, & Engage (RAISE) Family Caregivers Act initial report to Congress.* https://acl.gov/sites/default/files/RAISE-InitialReportToCongress2021_Final.pdf

Reinhard, S. C., Young, H. M., Levine, C., Kelly, K., Choula, R. B., Accius, J., Vice President, S., Emerita, D., Irene, B., & Director, E. (2019). *Home Alone Revisited: Family caregivers providing complex care.* AARP. https://www.aarp.org/ppi/info-2018/home-alone-family-caregivers-providing-complex-chronic-care.html

Riffin, C., Van Ness, P.H., Wolff, J.L., & Fried, T. (2018). Multifactorial examination of caregiver burden in a national sample of family and unpaid caregivers. *Journal of American Geriatric Society, 67,* 277-283.

Robert Wood Johnson Foundation. (2008). *Semi-structured interviews.* http://www.qualres.org/HomeSemi-3629.html

Robinson, B.C. (1983). Validation of a caregiver strain index. *Journal of Gerontology*, *38*(3), 344-348.

Rokstad, A. M. M., Røsvik, J., Fossberg, M., & Eriksen, S. (2021). The COVID-19 pandemic as experienced by the spouses of home-dwelling people with dementia – a qualitative study. *BMC Geriatrics*, *21*(1), 1–9. https://doi.org/10.1186/s12877-021-02551-w

Roll, S. & Grinstein-Weiss, M. (2020, August 25). Did CARES Act benefits reach vulnerable Americans? Evidence from a national survey. *The Brookings Institution.* https://www.brookings.edu/research/did-cares-act-benefits-reach-vulnerable-americans-evidence-from-a-national-survey/

Rosalynn Carter Institute for Caregiving. (2020, October). *Caregivers in crisis: Caregiving in the time of COVID-19.* https://www.rosalynncarter.org/wp-content/uploads/2020/10/Caregivers-in-Crisis-Report-October-2020-10-22-20.pdf

Rote, S.M., Angel, J.L., Moon, H., & Markides, K. (2019). Caregiving across diverse populations: New evidence from the National Study of Caregiving and Hispanic EPESE. *Innovation in Aging, 3*(2), 1-11. https://doi.org/10/1093/geroni/igz033

Sackett, V. (2017). *Caregiving in the LGBT community*. AARP. https://www.aarp.org/caregiving/stories/info-2017/lgbt-caregiving-fd.html

Saldana, J. (2013). *The coding manual for qualitative researchers: Second edition.* SAGE Publications.

Scandura, T.A. & Lankau, M.J. (1997). Relationships of gender, family responsibility

and flexible work hours to organizational commitment and job satisfaction. *Journal

of Organizational Behavior, 18*, 377-391.

Scharlach, A.E. (1994). Caregiving and employment: Competing or complementary

roles? *The Gerontologist, 34*(4), 378-385.

Schein, V.E. (1975). Relationships between sex role stereotypes and requisite

management characteristics among female managers. *Journal of Applied

Psychology, 60*(3), 340-344.

Schmepp, D. (2016). *Caregiving 101: On being a caregiver.* Family Caregiver Alliance.

https://www.caregiver.org/sites/caregiver.org/files/media/caregiving_101_161114_

web.pdf

Schneider, A., Hsu, A., & Horsley, S. (2020, October 2). Multiple demands causing

women to abandon workforce. *NPR.* https://www.npr.org/sections/coronavirus-live-

updates/2020/10/02/919517914/enough-already-multiple-demands-causing-women-

to-abandon-workforce

Schrank, B., Ebert-Vogel, A., Amering, M., Masel, E. K., Neubauer, M., Watzke, H., …

Schur, S. (2016). Gender differences in caregiver burden and its determinants in

family members of terminally ill cancer patients. *Psycho-Oncology*, 808–814.

https://doi.org/10.1002/pon.4005

Schulz, R. & Beach, S.R. (1999). Caregiving as a risk factor for mortality: The Caregiver

Health Effects Study. *Journal of the American Medical Association, 282*(23), 2215-

2219.

Schulz, R., Burgio, L., Burns, R., Eisdorfer, C., Gallagher-Thompson, D., Gitlin, L.N., &

Mahoney, D.F. (2003). Resources for enhancing Alzheimer's caregiver health

(REACH): Overview, site-specific outcomes, and future directions. *The*

Gerontologist, 43(4), 514-520. https://doi.org/10.1093/geront/43.4.514

Schulz, R., & Eden, J. (2016). *Families caring for an aging America.* National

Academies Press.

Schulz, R. & Sherwood, P.R. (2008). Physical and mental health effects of family

caregiving. *The American Journal of Nursing, 108*, 23-27.

Seccombe, K. (2011). *"So you think I drive a Cadillac?" Welfare recipients'*

perspectives on the system and its reform. Allyn & Bacon.

Settles, I.H., Sellers, R.M., & Damas, A. (2002). One role or two? The function of

psychological separation in role conflict. *Journal of Applied Psychology*, *87*(3),

574-582. https://doi.org/10.1037//0021-9010.87.3.574

Shakesprere, J., Katz, B., & Loprest, P. (2021, September). *Racial equity and job quality:*

Causes behind racial disparities and possibilities to address them. Urban Institute.

https://www.urban.org/sites/default/files/publication/104761/racial-equity-and-job-

quality.pdf

Shaw, E. & Mariano, H. (2021, June). *Before the "she-cession": A pre-pandemic*

snapshot shows more women in the workforce than ever (IWPR #R654). Institute

for Women's Policy Research. https://iwpr.org/iwpr-publications/briefing-

paper/before-the-she-cession-a-pre-pandemic-snapshot-shows-more-women-in-the-

workforce-than-ever/

Shiels, M.S., Haque, A.T., Haozous, E.A., Allert, P.S., Almeida, J.S., Garcia-Closas, M.,

    Napoles, A.M., Perez-Stable, E.J., Freedman, N.D., Berrington de Gonzalez, A.

    (2021). Racial and ethnic disparities in excess deaths during the COVID-19

    pandemic, March to December 2020. *Annals of Internal Medicine*.

    https://doi.org/10.7326/M21-2134

Society for Human Resource Management. (n.d.). *General: What is an employee*

    assistance program (EAP)? https://www.shrm.org/resourcesandtools/tools-and-

    samples/hr-qa/pages/whatisaneap.aspx

Skira, M. (2015). Dynamic wage and employment effects of eldercare. *International*

    Economic Review, 56(1), 63-93.

Soucheray, S. (2020 May). *U.S. job losses due to COVID-19 highest since Great*

    Depression. University of Minnesota, Center for Infectious Disease Research and

    Policy. https://www.cidrap.umn.edu/news-perspective/2020/05/us-job-losses-due-

    covid-19-highest-great-depression

Spencer, L., Ritchie, J., & O'Connor, W. (2003). Analysis: Practices, principles, and

    processes. In Ritchie, J., & Lewis, J. (Eds.). *Qualitative research practice: A guide*

    for social science students and researchers. (pp. 199-218). Sage Publications.

Steeves, R. (2000). Sampling. In Cohen, M.Z., Kahn, D.L., & Steeves, R.H. (Eds.),

    Hermeneutic phenomenological research: A practical guide for nurse researchers.

    (pp. 45-56). SAGE Publications, Inc. http://dx.doi.org/10.4135/9781452232768

Stephens, M.A.P., Franks, M.M., & Atienza, A.A. (1997). Where two roles intersect: Spillover between parent care and employment. *Psychology and Aging, 12*(1), 30-37.

Stephens, M.A.P., Townsend, A.L., Martire, L.M., & Druley, J.A. (2001). Balancing parent care with other roles: Interrole conflict of adult daughter caregivers. *Journal of Gerontology: PSYCHOLOGICAL SCIENCES, 56B*(1), P24-P34.

Stoiko, R. R., & Strough, J. N. (2019). His and her retirement: Effects of gender and familial caregiving profiles on retirement timing. *International Journal of Aging and Human Development*, *89*(2), 131–150. https://doi.org/10.1177/0091415018780009

Swinkels, J., van Tilburg, T., Verbakel, E., & Broese van Groenou, M. (2019). Explaining the gender gap in the caregiving burden of partner caregivers. *Journals of Gerontology: Social Sciences, 74*(2), 309-317. https://doi.org/10.1093/geronb/gbx036

Taylor, P. (2014). *The next America: Boomers, millennials, and the looming generational showdown* (1st ed.). Public Affairs.

The disproportionate impact of COVID-19 on communities of color, U.S. House of Representatives Committee on Ways and Means, 116th Cong. (2020) (testimony of Douglas Holtz-Eakin). https://www.americanactionforum.org/testimony/the-disproportionate-impact-of-covid-19-on-communities-of-color/

The New York Times. (2021a, August 18). *See how vaccinations are going in your county and state*. https://www.nytimes.com/interactive/2020/us/covid-19-vaccine-doses.html

The New York Times. (2021b, August 18). *Coronavirus in the U.S.: Latest map and case count.* https://www.nytimes.com/interactive/2021/us/covid-cases.html

The White House. (2021, March 31). *FACT SHEET: The American Jobs Plan* [Press release]. https://www.whitehouse.gov/briefing-room/statements-releases/2021/03/31/fact-sheet-the-american-jobs-plan/

Thomas, D. R. (2006). A general inductive approach for analyzing qualitative evaluation data. *American Journal of Evaluation*, *27*(2), 237–246. https://doi.org/10.1177/1098214005283748

Thomas, E., & Magilvy, J. K. (2011). Qualitative rigor or research validity in qualitative research. *Journal for Specialists in Pediatric Nursing*, *16*(2), 151–155. https://doi.org/10.1111/j.1744-6155.2011.00283.x

Thomas, L. & Ganster, D. C. (1995). Impact family supportive work variables on work-family conflict and strain: A control perspective. *Journal of Applied Psychology*, 80(1), 6-15.

Thomas, R., Cooper, M., Cardazone, G., Urban, K., Bohrer, A., Long, M., Yee, L., Krivkovich, A., Huang, J., Prince, S., Kumar, A., & Coury, S. (2020). *Women in the workplace: Corporate America is at a critical crossroads.* McKinsey & Company. https://www.mckinsey.com/featured-insights/diversity-and-inclusion/women-in-the-workplace

Thrush, G. (2021, June 24). Here's what made it into the bipartisan infrastructure plan. *The New York Times.* https://www.nytimes.com/2021/06/24/us/politics/what-is-in-the-infrastructure-plan.html?smid=url-share

Torpey, E. (2020, October). *Education level and projected openings, 2019-29.* U.S.

    Bureau of Labor Statistics.

    https://www.bls.gov/careeroutlook/2020/article/education-level-and-openings.htm

Torpey, E. (2021, June). *Education pays, 2020.* U.S. Bureau of Labor Statistics.

    https://www.bls.gov/careeroutlook/2021/data-on-display/education-pays.htm

Trent, A., & Cho, J. (2020). Interpretation in qualitative research: What, why, how. In

    Leavy P. (Ed.) *The Oxford Handbook of Qualitative Research* (2nd ed., pp. 956–

    982). Oxford University Press.

    https://doi.org/10.1093/oxfordhb/9780190847388.013.35

United States Bureau of Labor Statistics (2020a, April*). Job flexibilities and work*

    schedules in 2017-2018. https://www.bls.gov/spotlight/2020/job-flexibilities-and-

    work-schedules/pdf/job-flexibilities-and-work-schedules.pdf

United States Bureau of Labor Statistics. (2020b, July). *A profile of the working poor,*

    2018 (Report 1087). https://www.bls.gov/opub/reports/working-

    poor/2018/home.htm

Unite States Bureau of Labor Statistics. (2020c, May). The employment situation- April

    2020. https://www.bls.gov/news.release/archives/empsit_05082020.pdf

United States Bureau of Labor Statistics. (2021, September). What data does the BLS

    publish on family leave? https://www.bls.gov/ncs/ebs/factsheet/family-leave-

    benefits-fact-sheet.htm#:~:text=89%25-

    ,Source%3A%20U.S.%20Bureau%20of%20Labor%20Statistics%2C%20National%

    20Compensation%20Survey.,access%20to%20unpaid%20family%20leave

United States Census Bureau. (2019). *QuickFacts: United States.*

https://www.census.gov/quickfacts/fact/table/US/PST045219

United States Department of Labor. (2012). *Fact sheet #28: The Family and Medical*

Leave Act. https://www.dol.gov/sites/dolgov/files/WHD/legacy/files/whdfs28.pdf

United States Department of Labor. (n.d.). *Fair Labor Standard Reporting Act advisor.*

https://webapps.dol.gov/elaws/faq/esa/flsa/014.htm?_ga=2.5230195.154622606.163

7138090-1611157466.1634164672

United States Office of Personnel Management. (n.d.) *Frequently asked questions.*

https://www.opm.gov/faqs/QA.aspx?fid=4313c618-a96e-4c8e-b078-

1f76912a10d9&pid=2c2b1e5b-6ff1-4940-b478-34039a1e1174

Vaitheswaran, S., Lakshminarayanan, M., Ramanujam, V., Sargunan, S., & Venkatesan,

S. (2020). Experiences and needs of caregivers of persons with dementia in india

during the COVID-19 pandemic: A qualitative study. *American Journal of Geriatric*

Psychiatry, *28*(11), 1185–1194. https://doi.org/10.1016/j.jagp.2020.06.026

Van Houtven, C., Coe, N.B., & Skira, M. (2012). The effect of informal care on work and

wages. *Journal of Health Economics, 32*, 240-252.

Vandepitte, S., Van Den Noortgate, N., Putman, K., Verhaeghe, S., Verdonck, C., &

Annemans, L. (2016). Effectiveness of respite care in supporting informal caregivers

of persons with dementia: a systematic review. *International Journal of Geriatric*

Psychiatry, *31*(12), 1277–1288. https://doi.org/10.1002/gps.450

Vickrey, B.G., Strickland, T.L., Fitten, L.J., Adams, G.R., Ortiz, F., & Hays, R.D. (2007).

Ethnic variations in dementia caregiving experiences. *Journal of Human Behavior*

in the Social Environment, 15(2-3), 233-249.

https://doi.org/10.1300/J137v15n02_14

Vitaliano, P.P., Zhang, J., & Scanlan, J.M. (2003). Is caregiving hazardous to one's

physical health? A meta-analysis. *Psychological Bulletin, 129*(6).

https://doi.org/10.1037/0033-2909.129.6.946

Ward-Griffin, C., Brown, J. B., St-Amant, O., Sutherland, N., Martin-Matthews, A.,

Keefe, J., & Kerr, M. (2015). Nurses negotiating professional–familial care

boundaries: Striving for balance within double duty caregiving. *Journal of Family

Nursing*, *21*(1), 57–85. https://doi.org/10.1177/1074840714562645

Welch, L.C., Teno, J.M., & Mor, V. (2005). End-of-life care in Black and white: Race

matters for medical care of dying patients and their families. *Journal of the

American Geriatric Society, 53*, 1145-1153.

Wething, H. (2021). *Does paid sick leave affect job turnover?* [Working paper].

Washington Center for Equitable Growth. https://equitablegrowth.org/wp-

content/uploads/2021/08/091021-WP-Paid-sick-leave-job-turnover-wething.pdf

Willert, B. & Minnotte, L. (2019). Informal caregiving and strains: Exploring the impacts

of gender, race, and income. *Applied Research in Quality of Life*.

https://doi.org/10.1007/s11482-019-09786-1

Williams, J. (2010). *Reshaping the work-family debate: Why men and class matter.*

Harvard University Press.

Williams, J.C. (2014). Double jeopardy? An empirical study with implications for the

    debates over implicit bias and intersectionality. *Harvard Journal of Law & Gender,*

    37, 186-241.

Williams, J.C. & Boushey, H. (2010). *The three faces of work-family conflict: The poor,*

    the professionals, and the missing middle. Center for American Progress.

    https://www.americanprogress.org/issues/economy/reports/2010/01/25/7194/the-

    three-faces-of-work-family-conflict/

Williams, J.C., Devaux, R., Petrac, P., Feinberg, L. (2012). *Protecting family caregivers*

    from employment discrimination. AARP.

    https://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/prot

    ecting-caregivers-employment-discrimination-insight-AARP-ppi-ltc.pdf

Wolff, J. L., Drabo, E. F., & Van Houtven, C. H. (2019). Beyond parental leave: Paid

    family leave for an aging America. *Journal of the American Geriatrics Society*, 1–3.

    https://doi.org/10.1111/jgs.15873

Wolff, J. L., Mulcahy, J., Huang, J., Roth, D. L., Covinsky, K., & Kasper, J. D. (2017).

    Family caregivers of older adults, 1999–2015: Trends in characteristics,

    circumstances, and role-related appraisal. *The Gerontologist*,

    https://doi.org/10.1093/geront/gnx093

Wolla, S.A. & Sullivan, J. (2017). *Education, income, and wealth.* Federal Reserve Bank

    of St. Louis. https://research.stlouisfed.org/publications/page1-

    econ/2017/01/03/education-income-and-wealth/

World Bank. (2018). *Individuals using the internet (% of population)- United States.*

  https://data.worldbank.org/indicator/IT.NET.USER.ZS?end=2018&locations=US&

  start=2016

World Economic Forum. (2021). *The global gender gap report.*

  https://www.weforum.org/reports/global-gender-gap-report-2021

Wrigley-Field, E., Garcia, S., Leider, J. P., & Van Riper, D. (2021). COVID-19 mortality

  at the neighborhood level: racial and ethnic inequalities deepened in Minnesota in

  2020. *Health Affairs*, *40*(10), 1644–1653. https://doi.org/10.1377/hlthaff.2021.00365

Yavorsky, J.E., Qian, Y., & Sargent, A.C. (2021). The gendered pandemic: The

  implications of COVID-19 for work and family. *Sociology Compass 15,* 1-13,

  https://doi.org/10.1111/soc4.12881

Yee, J.L. & Schulz, R. (2000). Gender differences in psychiatric morbidity among family

  caregivers: A review and analysis. *The Gerontologist, 40*(2), 147-164.

Zamarro, G., Perez-Arce, F., Prados, M.J. (2020). *Gender differences in the impact of*

  COVID-19. USC Dornsife Center for Economic and Social Research.

  https://ktla.com/wp-content/uploads/sites/4/2020/06/ZamarroGenderDiffI

Zarit, S., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly:

  Correlates of feelings of burden. *The Gerontologist, 20*(6), 649-655.

  https://doi.org/10.1093/geront/20.6.649

Zarit, S.H., Todd, P.A, & Zarit, J.M. (1986). Subjective burden of husbands and wives as

  caregivers: A longitudinal study. *The Gerontologist, 26*(3), 260-266.

Zuba, M. & Schneider, U. (2013). What helps working informal caregivers?: The role of workplace characteristics in balancing work and adult-care responsibilities. *Journal of Family and Economic Issues*, *34*, 460-469. https://doi.org/10.1007/s10834-012-9347-7

Zuraw, L. & Rodriguez, C.H. (2021, May 28). *Caring for an aging nation.* Kaiser Health News. https://khn.org/news/article/caring-for-an-aging-nation/

Appendices

Appendix A

Researchers at the University of Denver are recruiting participants for a study on the experiences of working women who provide informal care to adults age 50 and older during the coronavirus pandemic.

If you are a woman who works at least 20 hours/week and cares for an adult age 50 or older outside of work, you may be eligible to participate in this research.

Eligible participants will take part in a 60-90 minute interview via video conferencing software (e.g. Zoom) or telephone, scheduled at a mutually agreeable time and date. Participants will be compensated with a gift card for their time.

If you are interested in participating in thisstudy, please contact Jessica at Jessica.king@du.edu or (970) 658-0267

Faculty Sponsor: Dr. Leslie Hasche, MSW, PhD Leslie.Hasche@du.edu; 303-871-4816

University of Denver

Consent Form for Participation in Research

> **Please take all the time you need to read through this document and decide whether you would like to participate in this research study.**

Title of Research Study: The Role of Workplace Policy and Racial Disparities Among Employed Female Caregivers During the Coronavirus pandemic

IRB Net #: 1702465-1

Principal Investigator: Jessica King McLaughlin, MSW, LCSW

Faculty Sponsor: Dr. Leslie Hasche, MSW, PhD

Study Site: Over the phone or via Zoom teleconferencing technology software

<u>Voluntary Participation</u>
You are being asked to participate in a research study. Participating in this research study is completely voluntary and you are not required to participate. This document contains important information about the study and what to expect if you decide to participate. Please consider the following information carefully. Feel free to ask questions before making your decision whether or not to participate.

<u>Purpose</u>

You are being asked to participate in a research study on the experiences of working female caregivers during the coronavirus pandemic. The purpose of this study is to understand how caregivers have been affected by the pandemic and how they manage their work in light of the many changes brought about by the coronavirus. Further, we want to understand how workplace policy may play a role in how caregivers are managing both their work and care duties.

Procedures

If you participate in this study, you will 1) provide a preferred method of contact, 2) complete the demographic questionnaire, 3) participate in an interview lasting up to 90 minutes with Ms. McLaughlin, and 4) be contacted for "member checking" via email, which involves looking over some preliminary findings and themes gathered from the interview data and check to ensure that those findings reflect your experiences after your interview. We ask for your contact information (phone number and/or email) so we can get in touch with you to schedule an interview time and to correspond with you about gift card compensation for your participation.

Risks or Discomforts

Participants may experience some emotional distress discussing their caregiving and working experiences. We do not anticipate this emotional distress to be greater than distress generated by daily conversation on related topics, nor do we anticipate additional risks.

Interviews will be held on Zoom teleconferencing software and will be video and audio recorded. Interviews that take place over the phone will be audio recorded. All video and audio recordings will be converted to written transcripts for purposes of analysis. All transcripts will be stored on password-protected cloud data storage

software, Microsoft OneDrive. Digital files of the video and audio recordings and the transcripts will be deleted and destroyed after transcription.

Benefits

This research is intended to learn how workplace policies may be helpful for working caregivers and what kind of support they may need in managing their responsibilities. No direct benefits would come from this study. Your decision whether or not to participate in this study will not affect your employment or any other parts of your life.

Incentives to Participate

Participants will be compensated with a $20 gift card for their time when the interview ends. The gift card will be sent either via email to the participant or mail if the participant prefers.

Confidentiality

We will make every effort to keep your information secure to the greatest extent possible. We request your contact information (email address and/or phone number) to get in touch with you; your contact information will not be used for any other purpose nor provided to anyone besides the researchers involved in this study. Each participant will receive an alpha numeric code, which will serve as your identification throughout the course of the study. Your identity and individual responses will remain private when and if this study's information and results are presented or published to the broader public audience. All data will remain in password-protected computers to which only those on the research team will have access. The link between your identifiers and the research data will be destroyed after the records retention period required by state and/or

federal law. Any researchers that assist with data analysis will be either student researchers at the University of Denver and/or employees of the University of Denver.

Limits to Confidentiality
Should any information contained in this study be the subject of a court order or lawful subpoena, the University of Denver might not be able to avoid compliance with the order or subpoena. The research information may be shared with federal agencies or local committees who are responsible for protecting research participants.

Additionally, if we learn that you intend to harm yourself or others, including, but not limited to child or elder abuse/neglect, suicide ideation, or threats against others, we must report that to the authorities as required by law.

Data Sharing
De-identified data from this study may be shared with the research community at large to advance science and health. We will remove or code any personal information (e.g.,, your name) that could identify you before files are shared with other researchers to ensure that, by scientific standards and known methods, no one will be able to identify you from the information or samples we share. Despite these measures, we cannot guarantee complete anonymity of your personal data.

Use of Your Information for Future Research
Your information collected for this project will NOT be used or share for future research, even if we remove identifiable information.

Consent to Video/Audio Recording

This study involves audio and/or video recording. If you do not agree to be recorded, you CANNOT take part in the study.

Questions
If you have any questions or concerns about this project, please feel free to ask questions by contacting the Principal Investigator, Jessica King McLaughlin, at Jessica.king@du.edu /(970) 658- 0267 or Faculty Sponsor, Dr. Leslie Hasche at <u>Leslie.hasche@du.edu/(303)</u> 871-4816.

If you are not satisfied with how this study is being conducted, or if you have any questions or concerns about your research participation or rights as a participant, you may contact the DU Human Research Protections Program by emailing <u>IRBAdmin@du.edu</u> or calling (303) 871-2121 to speak to someone other than the researchers.

Please take all the time you need to read through this document and decide whether you would like to participate in this research study.

If you decide to participate, your completion of the research procedures indicates your consent. Please keep this form for your records.

Interview Guide

Initial Prompt: Tell me about how you came to be a caregiver for xyz. How did you become their caregiver? How has that been different during the pandemic?

1. How has the coronavirus impacted you?

<u>Probes:</u>

  a. Have you been able to work from home during the pandemic?

  b. Do you work the same schedule as you worked prior to the pandemic? If not, why?

2. What workplace policies/accommodations/support mechanisms* does your employer provide to support you?

<u>Probes:</u>

  a. How did you become aware of these policies?

  b. How easy is it to access these policies and use them?

  c. What is the general workplace culture and environment around individuals who use these workplace policies?

  d. How have these policies helped you?

  *[Researcher may have to prompt with examples of workplace policies, such as unpaid leave, paid leave, paid sick time, flexible workplace schedule, flextime during the week, caregiver resources/case management, job sharing, ability to drop down to part-time status without losing benefits, personal time, etc.)

[If the participant says there are no supportive policies] What kind of policies/accommodations/support mechanisms would you like your employer to provide to support you? What would be helpful for you?

3. What impact has the coronavirus pandemic had on how you provide care/your caregiving responsibilities/ how you manage your caregiving duties?

Probes:

  a. Have your caregiving responsibilities remained the same? Increased? Decreased

    i. [If changed] How have they changed?

    ii. [If changed] Why did your responsibilities change?

4. [If the participant lost their job or is otherwise not employed at the time of interview due to the coronavirus] Is it easier or harder to provide care now? Why is it easier or harder?

  a. What could your employer have done to keep you employed and able to manage your caregiving duties during the pandemic?

5. Has it gotten easier or more difficult to manage caregiving and work duties over the course of the pandemic? Why did it get easier/more difficult?

6. Reflecting on all that you have shared about work and caregiving, how may have your identities, such as your gender or race, impacted your experiences providing care and working during the pandemic?

7. Does anyone help you in your caregiving duties, either professionally or informally?

      a. If so, how do they help?

8. Is there anything else that you feel like I missed or is important for me to know?

Appendix D

Structural Codes

Structural Code	Interview Question(s)
Caregiving Changes	"How has caregiving been different during the pandemic?" "Is it easier or harder to provide care now? Why?"
Caregiver Story	"Tell me about how you came to be a caregiver for xyz."
Employment	"How has your employer or place of employment supported you during this time?"
Identity of Caregiver	"Reflecting on all that you have shared about work and caregiving, how may have your identities (such as your gender, race, ethnicity, age, religion) impacted your experiences providing care and working during the pandemic? Does anyone help you in your caregiving duties, either professionally or informally?"
Support for Caregiving	"Does anyone help you in your caregiving duties, either professionally or informally?"

Appendix E

Emotion Codes

Emotion	Quote
Worry/Concern- This referred to caregivers' concerns of either contracting coronavirus themselves or their care recipient contracting the disease. Caregivers described the caution and vigilance that they had to maintain to keep themselves and their care recipients safe.	"…when COVID came along, my brother and I were feeling very worried about having different people come into her household with the virus and didn't want mom to have any exposure or as little exposure as possible." "If we get a package from Amazon, [my father] was racing to the door. And I would have to jump up and throw out my headphones. "No, don't answer the door! Let them leave the package!" I told him so many times, but he would still do it. So I'm like in this heightened state of alert."
Anxiety about the Future- Caregivers were both anxious about when the pandemic would end and what caregiving would be like after the pandemic was over, and caregivers resumed "normal" activities outside of the home.	"I don't know when this is going to end…Is it going to get worse? Is it gonna get better? Is it going to get worse and better? Is this going to be six months? Six years? Two weeks? I think that part's emotionally hard because I don't know what this looks like."
Guilt- This describes the feeling that caregivers had when they could not provide more stimulation or attention to their care recipient because they have to work or are	"Sometimes I feel really sad because I do have such a demanding job that I feel like I don't always give him the attention that he deserves."

limited in seeing them due to public health concerns.	"So many people I know whose parents are in country A and they're in country B…We all have this common feeling of anxiety and guilt, that we are not where we are needed."
Isolation- This refers to the sense of loss of social contact and opportunities for leisure with others outside of the house. Caregivers also shared that care recipients were struggling with as well.	"What's made it tough for me is that it's been very isolating. Very isolating…I get up, I go to work. Stop work. I take care of my mother."
Feeling Devalued and Overlooked- This refers to the feeling that caregivers were not appreciated by other family members for the caregiving work that they did, as well as being overlooked more broadly as essential elements of the healthcare system and not prioritized for vaccines.	"Neither one of my siblings has picked up the phone and said, 'Hey, how are you doing? How are you managing? Does Dad need anything? Do you need anything?' That has not happened. And that's been very hard." "It would have been nice if someone asked how I was doing." "I didn't technically qualify as [my mother's] caregiver, [home health aide's name] can get it…because she's a home health aide. But they're not considering caregivers like me as caregivers, which kind of stinks."
Overwhelmed- This refers to the feelings that caregivers described of being the only one to provide care and realizing that they were on their own in caregiving.	"Quite often, I feel like the weight of the whole household is on me."
Exhaustion – This refers to both the physical and mental exhaustion that caregivers experienced from caregiving during the pandemic, wherein caregivers frequently had few breaks from caregiving.	"I'm just so tired…I feel that I'm so drained; I have no emotional strength anymore…I sometimes just want to sleep."

Appendix F

Workplace Policies

Workplace Policy	Definition
Pandemic-Specific	Workplace-specific policies instituted at individual companies in response to the coronavirus pandemic
Federal Policy (FFCRA)	Policies passed at the federal level aimed at providing relief for employees and their family members
Work Travel	Travel employees take for work purposes
Work from Home	The optional or mandatory policy that employees work outside of the office. Also referred to as "working remotely."
Schedule Flexibility	The ability to start or stop work at times that are the employee's choice
Employee Assistance Programs (EAPs)	Resources (e.g., referrals, case management, counseling, legal advice, etc) funded by the employer that are aimed at promoting employee wellbeing
Caregiving Resources Available through EAP	Resources funded by the employer that are specifically aimed at caregiver assistance
Paid Time Off	Job-protected, paid time off for an employee to use at their discretion. Also often referred to as "vacation time."
Sick Leave	Job-protected, paid time off that an employee can use when they are sick and unable to work
Paid Family Leave	Job-protected paid time off that an employee can use to provide care for a family member. Can either be provided by an individual company or a state-mandated policy.
Company-Provided	
State-Mandated	
Part-Time Status	The ability of an employee to work less than fulltime hours in their current job role