

FACTORS ASSOCIATED WITH CAREGIVER
STRESS AND SELF-REPORTED COGNITION
DURING THE COVID-19 PANDEMIC

By

RACHAEL TURNER

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DURING THE COVID-19 PANDEMIC

Thesis Approved:

Celinda Reese-Melancon

Thesis Adviser

Amanda Baraldi

Larry L. Mullins

Name: RACHAEL TURNER

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Abstract: Caregivers are critical in helping persons with dementia (PWD) live at home longer, but the caregiving experience is associated with increased risk of physical (Vitaliano et al., 2003; Son et al., 2007; Fonareva & Oken, 2014) and cognitive decline among caregivers (Pertle et al., 2015; Lathan et al., 2016; Vitaliano et al., 2017). The present study examined the caregiver experience during the time of the Covid-19 pandemic to identify factors associated with caregiver stress, burden, and self-reported cognition (i.e., prospective and retrospective memory errors). In a sample of 56 caregivers of PWD, caregiver stress was positively associated with reports of greater life change resulting from Covid-19 and a greater frequency of care recipient depressive and disruptive behaviors; however, caregiver stress was not associated with care recipient memory problems. Additionally, caregiver burden was negatively associated with ratings of preparedness for the pandemic but not with availability of support services or the amount of time spent caregiving. Further, frequencies of prospective and retrospective memory mistakes were positively associated with perceived stress but not with caregiver burden. This work is a first step in identifying areas in which caregivers need assistance during a global health crisis and expanding the literature on caregiver cognition.

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CHAPTER I

Factors associated with caregiver stress and self-reported cognition during the COVID-19 pandemic

Over 17 million people are informal caregivers to older adults in America (National Academies of Sciences, Engineering, and Medicine, 2016). These caregivers are spouses, adult children, other family members, and friends providing needed assistance. Individuals, often older adults, who require assistance with daily tasks such as physical Activities of Daily Living (ADLs; Katz et al., 1963) and Instrumental Activities of Daily Living (IADLs; Lawton & Brody, 1969) rely on caregivers for their everyday life (National Academies of Sciences, Engineering, and Medicine, 2016). As the aging population continues to increase, the need for caregivers will continue to increase as well (National Academies of Sciences, Engineering, and Medicine, 2016; Harris, 2013). With so many individuals impacted by caregiving, it is important to better understand the ways in which this experience affects the caregiver, especially during times of crisis.

CHAPTER II

REVIEW OF THE LITERATURE

Past literature has shown that the impact caregiving has on caregivers can vary from positive experiences to more negative ones. Most literature has shown that caregivers face heightened risk for physical health problems as well as cognitive decline (Fonareva & Oken, 2014; Chen & Botticello, 2013; Vitaliano et al., 2017; Bertrand et al., 2012). The level of chronic stress experienced is a key aspect of the effect on caregivers, particularly for caregivers of individuals with dementia (Correa et al., 2015; Lathan et al., 2016; Pertle et al., 2017; Vitaliano et al., 2017). This makes the potential impact of the Covid-19 pandemic especially concerning for caregivers due to the diminished availability of resources such as Adult Day Centers and familial support systems that would normally assist in daily care so that caregivers may go to work or benefit from respite. The present literature will first include an examination of caregiver stress and burden and how they are related to caregivers' physical and cognitive health. Next, formal and informal support services will be examined as potential factors that can assist caregivers in coping. Finally, past literature on the impacts of natural disasters will be described to assist in understanding the potential effect that the Covid-19 pandemic could have on caregivers. Caregiving presents challenges that influence caregivers physically, financially, and socially (Garlo et al., 2010; Limpawattana et al., 2013). The chronic stress due to caregiving tasks presents difficulty and strain to the caregiver's life and has become known as *caregiver burden* (Zarit et al., 1980). Caregivers' experiences can include physical work assisting the care recipient

with tasks they are not able to do themselves and can also include cognitive tasks such as medication adherence, appointment reminders, or cooking meals. Most times, caregiving is not short-term, and caregivers manage this increase in tasks and assisting their loved one for multiple years (National Academies of Sciences, Engineering, and Medicine, 2016). Caregiver burden is experienced by many informal caregivers as they assist their loved ones, and this burden is often heightened for caregivers of persons with dementia (PWD) as they have added challenges due to the nature of the disease. Dementia disorders are caused by abnormal brain changes and impair cognitive skills and change behavior (Alzheimer's Association, 2020), which causes more strain and burden to be placed on this type of caregiver. The behavioral problems associated with dementia are related to higher caregiver burden, stress, and depression symptoms (Ornstein & Gaugler, 2012). This present study will focus on the impact of burden on caregivers of PWD including caregiver well-being, cognitive outcomes, and resource availability during the time of the Covid-19 pandemic.

A recent literature review (Fonareva and Oken, 2014) examining caregivers' health found that a large majority of studies identified significant differences between caregivers and non-caregivers. Caregivers had higher rates of sleep disturbance, lower sleep quality and worse overall health as determined in the literature reviewed (Fonareva & Oken, 2014). In particular, the review indicated that caregivers of PWD, specifically, had an increased risk for coronary heart disease, immune dysfunction, and an overall higher mortality rate. The behavior problems that are associated with dementia have been shown to impact the caregiver's health as well. Son et al. (2007) found that an increase in behavior problems in care recipients was related to poorer self-reported health among caregivers with feelings of overload being a significant mediator. This finding indicates the feelings of overload they face affect caregivers' health. Since dementia is often associated with age, it is common that spousal caregivers of PWD are also older and frailer themselves (Fonareva & Oken, 2014; Bottiggi et al., 2017). This forces them to face the typical

challenges of aging along with the challenges that come with being a caregiver. Self-reported levels of stress among caregivers are strong indicators of how they are affected by the caregiving experience. According to the Pearlin Stress Process Model (Pearlin et al., 1990), stress among caregivers is determined by a variety of factors such as resources, socioeconomic status, and primary or secondary stressors. Research comparing objective (e.g., behavior problems in care recipient) and subjective stressors (e.g., self-reports of overload) among caregivers, indicated that both objective and subjective stressors were related to poorer overall health, more negative health behaviors, and higher use of health care services among caregivers of PWD (Son et al., 2007). These findings highlight the importance of recognizing that multiple types of stressors impact caregivers' health and therefore information on multiple types of stressors is needed to give a full depiction of the factors associated with stress. Importantly, studies employing physiological markers of stress support findings from studies that have examined stress using self-report. When examining cortisol and alpha amylase in spouses of persons with MCI, findings indicated steeper cortisol slopes on days with more memory-related problems (Savla et al., 2013). Further, research examining cortisol levels and daily diary reports found that spouses of persons with mild cognitive impairment (MCI) experienced higher negative affect and lower positive affect when higher amounts of problem behaviors or unpleasant interactions with their spouse occurred (Savla et al., 2011). Caregivers also had increased distress indicated by cortisol levels when problem behaviors and non-care-related difficulties or cutbacks of activities occurred on the same day (Savla et al., 2011). These findings indicate the impact that the caregiving experience has on stress and why it is important to explore ways to reduce this stress. For example, past literature has found family functioning (Mitrani et al., 2006) and social support (Parrish & Adams, 2004) to be mediators of stress among caregivers, indicating that there are factors that can reduce the impact.

Cognitive performance can be particularly important for caregivers as they must remember their own everyday tasks as well as their loved one's needs, such as appointment reminders and medication management (Bottiggi et al., 2017). In a literature review by Fonareva and Oken (2014), findings indicated that caregivers of PWD performed worse on general cognitive processing, verbal recall, and executive function compared to noncaregivers. Caregivers of PWD also had a significantly higher likelihood of developing dementia themselves even after controlling for age, gender, genetics, and other risk factors (Fonareva & Oken, 2014). Further research has found that caregivers have lower performance on semantic memory, episodic memory, and immediate recall (Chen & Botticello, 2013; Pertle et al., 2015) indicating declines in retrospective memory (RM) functioning. Taken together this work indicates that caregivers of PWD have a heightened vulnerability for multiple deficits in cognitive processes.

Past literature has found stress to be a key factor in caregivers' cognitive decline. Research has indicated that caregivers of PWD self-report higher levels of stress and burden and have lower cognitive performance in episodic memory, working memory, and processing speed (Bottiggi et al., 2017). Further, Lathan et al. (2016) examined stress and cognitive decline among caregivers of PWD and found that higher levels of perceived stress were significantly correlated with lower performance on digit symbol coding and that caregivers had significantly lower performance on digit symbol coding, forward memory span, and reverse memory span tests compared to matched noncaregivers (Lathan et al., 2016). Further, Vitaliano and colleagues (2017) compared spousal caregivers of PWD to noncaregivers and found that caregivers of PWD had lower performance on a Trail-making Test and Digit Symbol Test, and also reported higher self-reported subjective cognitive problems such as difficulty with attention, concentration, forgetting, and mistakes compared to noncaregivers. However, the subjective cognitive concerns were associated with stress exposure but not with the objective cognitive measures, indicating a need to understand both objective and subjective cognitive measures (Vitaliano et al., 2017).

In addition to examining self-reported stress, research has shown the impact of stress on cognition through physiological components. Correa et al. (2015) examined the physiological components of possible cognitive decline to extend knowledge of caregiver burden among those caring for someone with Alzheimer's disease (AD). They examined cortisol levels and performance on a number of cognitive measures and found that caregivers of persons with AD had lower attention, working memory, and executive function as well as higher cortisol levels compared to a control sample of noncaregivers. This indicates stress as a potential key factor for cognition among caregivers of PWD and emphasizes the importance of subjective and objective cognitive measures in fully understanding the caregiving experience.

While past literature has explored many aspects of cognition among caregivers, less has been done specifically to examine prospective memory (PM) in this population. PM is the act of remembering to perform an intended action in the future and includes everyday tasks such as medication management, remembering appointments, or remembering to pick up an item at the store (McDaniel & Einstein, 2007). Because PM tasks must be completed while simultaneously completing an ongoing task, they have an added difficulty and are especially vulnerable to memory failures (Jager & Kliegel, 2008). There are typically two types of PM, event-based PM tasks and time-based PM tasks (Rummel & McDaniel, 2019). Event-based PM tasks depend on completing the intended action of the PM task with the occurrence of a target event (i.e., remembering to stop by the grocery store when you pass it on your way home). Time-based PM tasks depend on completing the intended action at a certain time or after a set amount of time has passed (i.e., remembering to take medications at 8 A.M.).

PM occurs in a set of phases from the initial formation of the intended action to the completion of the memory task (Rummel & McDaniel, 2019). The first phase is intention-formation and includes the process of encoding the PM task. The second phase is the intention-retention phase in which the PM task execution is delayed. The third phase is the intention-

retrieval phase in which the task must be retrieved and completed. The intention could fail at any one of these phases, leading to the failure of the PM task. An example of these three phases can be shown in the PM task of remembering to take food out of the oven in 20 minutes. You must first properly encode the intention of taking the food out with the correct amount of time. Then, over the course of the 20 minutes while completing other tasks, one must remember the intention and monitor or utilize another strategy to check for the appropriate opportunity to complete the intention. Once the 20 minutes is up, one must take the food out of the oven. While the task itself is simple, it could go wrong in a number of ways. Forgetting to set a timer to assist in remembering, failing to check the time when the food was placed in the oven to know when to take it out, getting caught up in another task and failing to maintain the intention during the delay, or even failing to remember what the task was once the 20 minutes has passed could all result in task failure. For caregivers, they must complete their own PM tasks while also monitoring or even completing the PM tasks of their care recipient. Monitoring their loved one becomes even more complex as the care recipient's dementia worsens. A care recipient may start a task like cooking but get distracted during the intention-retention phase and fail to take the food out of the oven, or once the task is completed, they could forget to turn the oven off. This situation and others like it result in a seemingly simple task becoming potentially dangerous, and it often results in the caregivers adding to their PM load. This example emphasizes just how important PM performance can be for many everyday tasks and how that performance could impact one's ability to live independently.

Past literature has explored age-related differences in PM performance at great length. This area of research is particularly relevant for research on caregivers of PWD as this population of caregivers are often spouses or an adult child of the PWD and therefore may be older or middle-aged adults. Since PM tasks have higher demand of self-initiated retrieval, it was initially thought that older adults would have significantly lower performance compared to younger adults

(Craik, 1986). In laboratory settings, younger adults perform better than older adults on both event-based and time-based PM tasks, especially for event-based tasks with heightened difficulty requiring more strategic processing (Henry et al., 2004). However, older adults often perform better than younger adults in naturalistic PM studies (Henry et al., 2004; Uttil, 2008). Since caregivers of PWD are more likely to be older themselves (Fonareva & Oken, 2014; Bottiggi et al., 2017), it is especially important to understand any age-related effects on caregivers' PM performance.

While research has not yet examined PM among caregivers of PWD, the research on caregivers of children with special healthcare needs gives insight into how PM may impact other caregiver populations. For example, Lovell and colleagues (2014) found that caregivers of children with Autism Spectrum Disorder (ASD) self-report more prospective and retrospective memory failures compared to parents of typically developing children. Further, higher levels of stress were related to higher reports of memory mistakes in caregivers (Lovell et al., 2014). When comparing event-based (e.g., retrieve a pen when cued by a bell) and time-based PM tasks (e.g., returning keys to the researcher at 2:30 p.m.), caregivers of children with ASD had lower performance on event-based PM tasks compared to noncaregivers, but there were no differences between the groups on time-based PM tasks (Lovell et al., 2019). This indicates that certain types of PM may be more vulnerable than others. Additional work also documents that caregivers of children with special healthcare needs (i.e., diagnosis of autism, chronic illness, multiple disabilities, behavioral disability) self-report more PM failures than caregivers of typically developing children (McBean & Schlosnagle, 2016). Together, these studies suggest that caregivers of PWD likely also have lower performance on PM tasks and will report more PM failures. However, currently no work has previously examined PM among caregivers of PWD. Caregivers often report higher stress compared to noncaregivers (Zarit et al., 1980; Vitaliano et al., 2003; Leggett et al., 2010; Cousino et al., 2016), which could factor into their PM

performance as it did for caregivers of children with autism (Lovell et al., 2014). Since caregivers of PWD are more likely to be older themselves (Bottiggi et al., 2017), their PM performance is essential not only to their ability to care for their loved one but also for their own ability to live independently, making it important to further explore and understand how this form of cognition relates to caregivers.

In addition to placing strain on health and cognition, caregiving can place added strain on finances due to increased healthcare costs and decreased work hours (Harris, 2013). Caregivers who are employed and those whose care recipients have a higher demand for assistance with IADLs are likely to report higher levels of burden than those who are unemployed or have lower demands (Hsu et al., 2014). This poses a problem for many individuals who need to work by adding to their level of overall burden. This is one reason Adult Day Centers (ADCs) can be particularly useful for caregivers. Adult Day Centers provide services outside of the home to individuals requiring care throughout the day and provide socialization, medical care, and therapeutic activities (Zarit et al., 1998). These services allow older adults, particularly those with functional or cognitive limitations, to live in their own home within the community longer (Ellen et al., 2017). Since caregivers face heightened risk for physical and cognitive decline, utilizing the resources that best assist caregivers could help them tremendously not only short-term in the day to day, but also long-term in their overall health. ADCs are one resource that has gained interest and have been utilized to minimize isolation, depression, and undue cognitive and physical decline among older adults living in the community (Ellen et al., 2017).

Since past research has indicated that caregivers report higher levels of stress and burden compared to noncaregivers (Vitaliano et al., 2003; Hsu et al., 2014), it is important to have social support and resources such as ADCs. In addition to providing a safe place for older adults to be cared for and have social opportunities, ADCs assist in lowering daily stressors caregivers experience. For example, Liu et al. (2018) found that caregivers of PWD report higher chronic

stress than the general population and that on the days they did not use ADCs, caregivers had flatter cortisol diurnal pattern compared to days they did use ADCs. This finding indicates lower stress when utilizing ADC. ADCs have also been shown to lower perceptions of worry and guilt among caregivers as well as reduce the amount of time that the care recipient would be left alone while the caregiver is at work (Valadez et al., 2005). Past literature has also found that on the days that caregivers use ADCs, they report lower exposure to stress and fewer behavioral problems from their care recipient (Zarit et al., 2011). Taken together, these studies indicate that ADCs provide much needed support in the day to day for caregivers.

Over time, caregivers utilizing ADCs report significantly lower overload, strain, and depression compared to caregivers not utilizing ADCs (Zarit et al., 1998; Maseda et al., 2015). However, caregivers who already receive more help from family and friends are more likely to use ADCs, highlighting the importance of social support mentioned previously not just from formal resources such as ADCs, but also from the individuals surrounding caregivers (Maseda et al., 2015). Further evidence for the benefits of ADCs comes from Gaugler et al. (2007) who found that utilizing ADCs, in-home assistance, and respite care can allow for lower stress among caregivers. Overall, these findings suggest that caregivers may be able to lower depressive symptoms, stress, and overall burden by utilizing outside resources that are available in their communities (Zarit et al., 1998; Gaugler et al., 2007; Liu et al., 2007; Maseda et al., 2015; Ellen et al., 2017).

Unfortunately, many of the support services, specifically many ADCs, that caregivers typically utilize to assist in caring for their loved one are not available during the Covid-19 pandemic (Lightfoot & Moone, 2020). Those who are able to find support services such as ADCs or in-home health, risk exposing their loved one to more people, which could increase their risk of becoming infected. The pandemic is particularly of concern for older adults as it is estimated that 8 out of 10 deaths from Covid-19 have been among individuals aged 65 or older (Centers for

Disease Control, 2020). While there are many factors such as prior health conditions and current living environment that affect mortality, the older adult community must take precautions to lower their risk whenever possible.

While the literature on the impact of Covid-19 on caregivers is still developing, past literature on natural disasters may provide insight into the effects these unexpected events can have on caregivers. Research indicates that natural disasters have particularly harmful effects for caregivers and older adults (Gibson et al., 2018; Christensen & Castaneda, 2014). Gibson et al. (2018) found that caregivers of PWD are especially at risk for being unprepared during disaster. This is because they must balance caregiving responsibilities while also trying to prepare, which can cause delays and lengthen the process. Researchers have also found that the progression of the disease for a PWD greatly influences the process caregivers go through during disaster preparedness (Christensen & Castaneda, 2014). Those who have progressed further into their disease often resist changes more strongly and are no longer able to assist the caregiver with preparations like they normally would (Christensen & Castaneda, 2014). This could easily mean more work for the caregiver not only with disaster preparations since they no longer have assistance, but also in their caregiving duties due to the changes causing an increase in problem behaviors for their loved one.

The Covid-19 pandemic is likely to prove to be a similar situation for older adults and caregivers as they must navigate the preparations and life-altering changes of this specific disaster. More than half of caregivers already report higher financial strain from job loss and medical expenses (Kent et al., 2020), something that has likely increased during the pandemic. In addition, many resources and activities are limited, and sheltering-in-place is encouraged particularly for older adults and at-risk populations (Centers for Disease Control and Prevention, 2020), increasing the likelihood that caregivers and their care recipients are facing home isolation (Chan et al., 2020). However, this causes its own problems. Many caregivers rely on resources

such as ADCs and home care visits in order to assist in caring for their loved ones (Cousino Klein et al., 2016). With these resources now limited or disrupted (Greenberg et al., 2020), they may not have the resources to fully care for their loved one (Chan et al., 2020), or they may be required to provide more care than needed previously (Greensburg et al., 2020). This disruption in resources poses even more problems for caregivers that work who may not have flexibility in work hours or be able to work from home resulting in a struggle to balance work and caregiving demands. As such, it is expected that the changes during the Covid-19 pandemic will impact both caregivers and care recipients, particularly with regard to levels of reported stress, burden, and problem behaviors.

In summary, the caregiving experience already provides many challenges due to the increased risk from stress and burden (Zarit et al., 1998; Leggett et al., 2010) as well as potentially lower cognitive performance (Pertle et al., 2015; Lathan et al., 2016; Correa et al., 2015; Vitaliano et al., 2017). The challenges associated with the Covid-19 pandemic are of particular concern for this population and could cause additional strain for caregivers as they navigate the changes that come. It is important to ensure that research captures many aspects of stress exposure such as time spent on caregiving tasks, behavioral and memory problems, and the types of tasks with which the caregiver must assist as stress has been shown to be a key factor in determining caregiver burden. It is also important to examine how the circumstances of the Covid-19 pandemic are associated with stress, burden, cognition, and resource availability as these items could have a large impact on the caregiver both in terms of short-term and long-term outcomes.

Study Aim 1. Identify factors associated with stress and burden for caregivers during the Covid-19 pandemic. In terms of stress, perceived pandemic-related life disruption (PRLD) and increased memory and behavior problems exhibited by the care recipient were expected to relate to stress among caregivers of PWD. The disruption to daily life was expected

to have a large impact on caregivers, as caregivers may struggle to balance the changes during the pandemic with higher risks of home isolation and lower resources while also caring for their loved one (Centers for Disease Control and Prevention, 2020; Chan et al., 2020). Research also indicates that there are often increases in change in everyday routine during disaster, which can lead to increased problem behaviors among care recipients (Christensen & Castaneda, 2014). Self-reported pandemic-related life disruption was measured by asking questions about how stress, burden, time spent caregiving, memory mistakes, and memory and behavior problems of the care recipient had changed since the onset of the Covid-19 pandemic. Memory and problem behaviors among care recipients were measured with the Revised Memory and Behavior Problems Checklist (Teri et al., 1992). We expected that higher levels of perceived change during Covid-19 and increases in memory and behavior problems would be related to higher levels of reported stress.

In terms of caregiver burden, the resources available to caregivers and their preparedness for the Covid-19 pandemic were expected to relate to levels of burden among caregivers of PWD. Past literature has shown that community resources such as Adult Day Centers provide assistance to caregivers and greatly reduce burden (Cousino Klein et al., 2016). Having a key resource like ADCs unavailable likely increases levels of burden among caregivers who rely on this service. Formal and informal support services, as well as preparedness for Covid-19, were expected to be related to burden. Formal and informal support services were determined based on participants' reports of the number of services their ADC offered during the Covid-19 pandemic, assistance of family and friends, paid assistance at home, and other reports of support. We expected that decreased availability of support services would be related to higher reports of burden. Past literature on caregivers during natural disasters documents that older adults and their caregivers are particularly disadvantaged and more likely to be unprepared (Gibson et al., 2018). This puts them at risk for higher amounts of burden during the Covid-19 pandemic as they must prepare

similarly to how they would for a disaster while simultaneously caring for their loved one. Preparedness was determined from caregivers' reports of how prepared they were to care for their loved one during the Covid-19 pandemic. We expected that lower reports of preparedness would be associated with higher reports of burden. In addition, not having formal and informal support services available was expected to be related to an increase in the amount of time spent on caregiving tasks, as caregivers would no longer be able to take their loved one to an ADC for the day so they could do things like go to work or run errands. An increased amount of time spent caregiving was expected to be related to higher reports of burden.

Study Aim 2. Identify the relationship between negative aspects of the caregiver experience and self-reported cognition. Past literature indicates that high levels of chronic stress and burden can impact many cognitive functions among caregivers (Correa et al., 2015; Chen & Botticello, 2013; Bottiggi et al., 2017). While caregivers' PM abilities are an aspect of cognition that is critical to the maintenance of independent living there is a gap in the literature on this important aspect of memory. Further research is needed to investigate PM since caregivers experience an increase in PM demands due to completing their own tasks as well as those of the care recipient. Past research on caregivers of children with ASD indicates that caregivers' stress is related to their reports of PM mistakes (Lovell et al., 2019). Similarly, we expected that higher amounts of stress and burden would be related to higher amounts of self-reported PM mistakes among caregivers of PWD. Past literature has already documented declines in retrospective functioning among caregivers as shown in research on semantic memory, episodic memory, and immediate recall (Chen & Botticello, 2013; Pertle et al., 2015). We expected that higher amounts of stress and burden would be related to higher amounts of self-reported RM mistakes. This study extends knowledge of how caregiver stress and burden are related to cognition, specifically focusing on self-reported prospective and RM mistakes among caregivers of PWD.

CHAPTER III

METHODOLOGY

Participants

Adult Day Centers from across the continental United States were contacted via phone or email after obtaining contact information from public listings online. Directors were informed about the study and criteria for participants. Then, they were able to pass along the information and a link to an online questionnaire to caregivers who they believed met the criteria for the study. The use of Adult Day Centers to recruit participants assisted in the identification of caregivers of PWD as well as confirming the population consisted of caregivers who lost a resource they typically use. Approximately 83 participants were recruited during May, June, and July of 2020 with the assistance of directors of Adult Day Centers. Participants who were not primary caregivers of a person with a diagnosis of Alzheimer's disease or dementia did not fit criteria of the study and were therefore excluded. This excluded 26 participants who indicated they were another type of caregiver (e.g., caregiver of a person with developmental disability, physical disability, stroke, etc.). One additional participant was excluded due to response invariance across multiple measures in the survey. Of the original sample, 56 participants were caregivers of PWD and were included in the analyses. Table 1 presents the demographic information of the caregivers. Participants ranged in age from 32 to 92 years ($M_{age} = 64.2$). This aligns with past literature as caregivers are typically the spouse or adult child of the care recipient

(Harris, 2013). Participants consisted of more females than males with 50 female participants and six male participants, also aligning with past literature since caregivers are more often women (Harris, 2013). Participants identified as White/Caucasian (78.6%), Hispanic/Latino (8.9%), Black/African American (5.4%), Asian (3.6%), multiple ethnicities (2.8%), Native American (1.8%), and one participant chose not to indicate. The study was conducted online in the form of a questionnaire. Participants were invited to enter a drawing for a \$25 gift card as compensation for their participation.

Materials and Procedure

After following the link to the online survey, participants were presented with an informed consent page. They were able to give their consent by clicking “Yes, I agree to participate in this study.” If participants did not consent, they were taken to the end of the survey and thanked for their time. If the participants chose to consent, they first provided demographic information both for themselves and the person for whom they provide care.

Next, they completed a section of the survey that allowed them to provide information on the caregiving role they have. This included their relationship to the care recipient, the diagnosis of the care recipient, the types of caregiving tasks that are required, and the amount of time they spend in caregiving roles.

Next, participants completed a series of measures. First, they completed the Zarit Burden Interview (ZBI), which is designed to measure the amount of burden experienced by caregivers specifically due to caregiving tasks (Zarit et al., 1980; Hebert et al., 2000; Bedard et al., 2001). Participants rated 12 items on a 5-point Likert-type scale ranging from 0 (*never*) to 4 (*nearly always*) on how often they experience feelings of stress or burden (i.e., “*Do you feel that because of the time you spend with your loved one that you don’t have enough time for yourself?*”; “*Do*

you feel uncertain about what to do about your loved one?”). This measure displayed good observed reliability ($\alpha = .851$).

Next, they completed the Revised Memory and Behavior Problems Checklist (RMBPC; Teri et al., 1992), which measures the frequency of memory or behavior problems that often occur in individuals with dementia. The RMBPC includes three subscales: Care Recipient Memory, Disruption, and Depression. For this measure, participants indicated how often 19 behaviors out of the original 24-item measure occur (i.e., “*Asking the same question over and over*”; “*Trouble remembering significant past events*”; “*Waking you or other family members up at night*”). Five items were not included due to experimenter error¹. Participants indicated the frequency of the items ranging from 0 (*never occurred*) to 4 (*daily or more often*) with the option of selecting “*don’t know/not applicable*” (DK). This measure was observed to be reliable ($\alpha = .786$) with each care recipient subscale also demonstrating acceptable reliability (Memory subscale: $\alpha = .741$; Disruption subscale: $\alpha = .783$; Depression subscale: $\alpha = .769$).

Then, participants were asked to complete the Perceived Stress Scale, a 10-item survey related to the individual’s stress over the last month (i.e., “*How often have you felt you were unable to control important things in your life?*”; “*How often have you found that you could not cope with all the things you had to do?*”) by providing ratings on a 5-point Likert-type scale ranging from 0 (*never*) to 4 (*very often*) (Cohen, Kamarak, & Mermelstein, 1983). This measure had a good observed reliability ($\alpha = .865$).

Next, they completed the Connor-Davidson Resilience Scale (Connor & Davidson, 2003) by rating how true they believe statements related to resilience were for them on 24 of the original 25-item questionnaire (i.e., “*Coping with stress strengthens me*”; “*Past success gives*

¹ See Appendix F for a list of items included in the survey from this measure

confidence for new challenges”) on a 5-point Likert-type scale ranging from 0 (*not at all true*) to 4 (*true nearly all of the time*).² This measure demonstrated excellent reliability ($\alpha = .916$).

Afterward, participants completed a section regarding their use of Adult Day Services. The questions for this were modified from the Adult Day Service Process and Use Measure (Gaugler & Dykes, 2019). Participants rated statements about their prior use of Adult Day Services (i.e., “*The relationships my relative has developed at Adult Day Services have benefitted him/her*”; “*I wish I had used Adult Day Services earlier for my relative*”). They also provided information on their frequency of use of services prior to the Covid-19 pandemic, their reasons for using services, and what services or resources ADCs were providing for their clients during the closures.

Next, participants completed a section regarding participants’ perceptions of Pandemic-Related Life Disruption (PRLD), their preparedness for Covid-19, and the resources available from their family or friends to assist. To assess PRLD, participants answered a question added to the end of multiple measures (e.g., Time Spent Caregiving, ZBI, RMBPC, Perceived Stress Scale, and Prospective and Retrospective Memory Questionnaire) asking them to rate the extent to which certain factors had changed since the start of the Covid-19 pandemic (i.e., “*How has the time you’ve spent doing caregiving related tasks changed since the Covid-19 pandemic started?*”; “*Have your feelings of strain from caregiving tasks changed since the Covid-19 pandemic started?*”; “*How have your memory mistakes changed since the Covid-19 pandemic started?*”). Participants then rated from 1 (*they have decreased a lot*) to 5 (*they have increased a lot*) on a Likert-type scale how much each dimension had changed. The PRLD measure was created for this study and had questionable observed reliability ($\alpha = .686$). To explore how prepared

² Connor-Davidson Resilience Scale was given to participants for exploratory purposes, but there were no specific hypotheses for this measure. See Appendix H for a list of items included in the survey from this measure.

caregivers were, participants rated how prepared they felt they were to care for themselves and their loved one during the pandemic on a 5-item questionnaire (i.e., “*How prepared do you feel you are to keep your loved one, whom you normally provide care for, healthy?*”), from 1 (*not at all prepared*) to 5 (*extremely prepared*). The preparedness measure was created for this study and also had questionable observed reliability ($\alpha = .654$). To explore what resources caregivers had within their personal social network to help care for the care recipient a checklist of resources they may have available to them was created for this study. Participants indicated any outside help and whether other family members were able to assist by selecting from a list of options (i.e., family members of friends, paid assistance, online activities). Participants were able to indicate resources they had access to from their ADC (i.e., online activities, at home activities, information about resources, check-ins) or outside resources (i.e., family or friends, paid assistance, online activities) by choosing from listed options. Participants were also able to list any additional resources not listed.

Last, participants completed a measure related to memory mistakes. The Prospective and Retrospective Memory Questionnaire (PRMQ; Smith et al., 2000) measures the frequency of common prospective and retrospective memory mistakes that can occur in daily life. Participants rated on a 5-point Likert-type scale ranging from 1 (*never*) to 5 (*very often*) how true the statements on the 16-item questionnaire were for them (i.e., “*Do you forget to tell someone something you had meant to mention a few minutes ago?*”; “*Do you forget something that you were told a few minutes before?*”). The PRMQ had excellent observed reliability ($\alpha = .934$) with the subscales also indicating good observed reliability (Prospective Memory subscale: $\alpha = .893$; Retrospective Memory subscale: $\alpha = .883$). Once the surveys were completed, the participants were debriefed and directed to follow a link to submit their contact information for compensation, if they chose to do so.

CHAPTER IV

RESULTS

Data Cleaning

Participants who did not complete the survey were not included in analyses. This includes participants who skipped entire measures within the survey, skipped a majority of questions throughout the survey, or stopped the survey without finishing. Mean replacement was utilized to replace four missing data points from four separate participants in four separate measures. This ensured that participants had complete sets of data for analyses and avoided missing data for certain measures during the scoring process. This was done by replacing the missing item with the participant's mean for that measure.

Statistical Analyses

Aim 1a: Identify factors associated with stress among caregivers during the Covid-19 pandemic.

To examine the factors associated with stress among caregivers of PWD, a series of Pearson correlations was conducted (see Table 2 for all correlations). The Perceived Stress Scale was used to determine self-reported stress with a sum total score calculated to represent the level of perceived stress. The PRLD measure was used to determine disruption due to the pandemic with a sum total score calculated (see Table 3 for participants' reports of disruption for each item). To examine how self-reported pandemic-related life disruption related to self-reported

stress, a correlation between the PRLD measure and stress scores was conducted. A significant positive relationship was found between stress and PRLD indicating that reports of greater disruption resulting from the pandemic were associated with higher levels of reported stress, $r(54) = .275, p = .04$. To examine how memory and behavior problems among PWD relate to stress, correlations between the RMBPC subscale scores and self-reported stress were conducted. A proportion score was calculated for each participant on each of the three subscales. This was done by creating a total score for each participant by summing the total frequency of care recipient behaviors, excluding items indicated as DK by the participant. This total was then divided by the number of items in the subscale minus the number of DK items to create an average score. DK items were not included in the proportion score in order to prevent potential incorrect interpretations about participants' responses. For example, some participants may have endorsed DK because the behavior was not observable and therefore an accurate frequency estimate could not be made. Contrary to the hypothesis, a significant relationship between the Memory subscale of the RMBPC and perceived stress was not found, $r(54) = .068, p > .05$. A significant positive relationship was found between stress and the Depression subscale, indicating higher levels of reported stress were related to greater frequency of care recipient depressive behaviors, $r(54) = .354, p = .007$. A positive relationship was also found between stress and the Disruption subscale, indicating higher levels of reported stress were related to greater frequency of care recipient disruptive behaviors, $r(54) = .365, p = .006$.

Aim 1b: Identify factors associated with burden among caregivers during the Covid-19 pandemic.

To examine the factors associated with burden among caregivers of PWD, a series of Pearson correlations was conducted. The Zarit Burden Interview (ZBI) was utilized to measure caregiver burden and a sum of the ratings was calculated to create an overall score for burden. Availability of support services was determined by summing caregivers' reports of the number of

services available from their Adult Day Centers plus the number of outside resources available through family, friends, paid assistance, and other sources. A sum score of the support services was utilized with a range from 0 to 9 based on the number of support services reported. However, there was a restricted range in the number of support services available with an actual range of 0 to 5 support services reported and 1 support service being the most endorsed response. To examine how formal and informal support services relate to burden, a correlation between availability of formal and informal support services during Covid-19 and ZBI scores was conducted. Contrary to the hypothesis, a significant relationship between formal and informal support services and caregiver burden was not found, $r(54) = -.026, p > .05$.

To examine how preparedness relates to burden, a correlation between Covid-19 preparedness and ZBI scores was also conducted. A sum score was calculated from five items on the preparedness measure to indicate level of preparedness during the Covid-19 pandemic. A negative relationship was found between preparedness and caregiver burden in that lower ratings of preparedness were associated with higher levels of self-reported caregiver burden, $r(54) = -.301, p = .024$.

To examine how time spent caregiving relates to caregiver burden, a correlation was conducted between time spent caregiving and ZBI scores. Time spent caregiving was determined through the report of hours of care provided per day. Contrary to the hypothesis, a significant relationship between time spent caregiving and caregiver burden was not found, $r(53) = -.038, p > .05$.

Aim 1c: Examine the factors contributing to burden among caregivers during the Covid-19 pandemic.

Initial correlation analyses revealed perceived stress to be related to many factors among caregivers. Therefore, further analyses were done to examine what factors predict levels of stress

among caregivers instead of examining factors related to caregiver burden. To examine factors contributing to stress among caregivers during the Covid-19 pandemic, a hierarchical multiple regression analysis was conducted with PRLD and burden as predictors. Predictor variables were entered into separate blocks to discern their relative contributions to perceived stress over and above other predictors. Demographic variables were used as control variables including caregiver age and education were entered into the first block. Table 4 presents the results of the first block, which revealed the first block of demographic variables to not be statistically significant predictors of stress, $R^2 = .01$, $F(2, 53) = .28$, $p = .76$. The predictor variable PRLD was entered for the second block. PRLD accounted for an additional 6.8% of the variability in self-reported stress over and above the other predictors and was trending toward significance, $\Delta R^2 = .07$, $F(1, 52) = 3.85$, $p = .06$. For the third block, the predictor variable burden was added to the analysis. The results revealed the model to be statistically significant with burden accounting for an additional 32.4% of variance of perceived stress among caregivers over and above the previous predictors, $\Delta R^2 = .32$, $F(1, 51) = 27.73$, $p = < .001$.

Aim 2: Identify the relationship between negative aspects of the caregiver experience and self-reported cognition.

To understand the relationship between self-reported cognition and stress and burden a series of Pearson correlations was conducted. The PRMQ was utilized to measure self-reported cognition. The PRMQ items were rated 1 (*never*) to 5 (*very often*) with higher scores indicating more memory mistakes. There are two subscales within the PRMQ reflecting frequency of prospective and retrospective memory mistakes. The relevant items were summed to create a score for each of the two subscales. The Perceived Stress Scale and the Zarit Burden Interview were again utilized to measure caregiver stress and burden. A significant positive relationship was found between PM mistakes and perceived stress in that greater frequency of PM mistakes was related to higher levels of perceived stress, $r(54) = .301$, $p = .024$. A significant positive

relationship was also found between RM mistakes and perceived stress in that greater frequency of RM mistakes was related to higher levels of perceived stress, $r(54) = .269, p = .045$. Contrary to hypotheses, burden was not significantly related to either PM mistakes, $r(54) = .223, p > .05$, or RM mistakes, $r(54) = .136, p > .05$.

To understand the relationship between self-reported PM and stress and burden, a hierarchical linear regression was conducted. Predictor variables were entered into separate blocks to discern their relative contributions to PM. The results are presented in Table 5. Demographic variables including caregiver age and education were entered into the first block to control for these variables. The first block was found to be not significant, $R^2 = .03, F(2, 53) = 0.88, p = .42$. For the second block, the predictor variable perceived stress was added to the analysis. The results revealed the model to be statistically significant with perceived stress accounting for an additional 8.2% of the variation in self-reported PM among caregivers, $\Delta R^2 = .08, F(1, 52) = 4.82, p = .03$. For the third block, the predictor variable burden was added to the analysis. The results revealed the model to be not statistically significant with burden accounting for no additional variance in PM, $\Delta R^2 = .00, F(1, 51) = .00, p = .95$.

To understand the relationship between self-reported RM and stress and burden, a hierarchical linear regression was conducted. Predictor variables were entered into separate blocks to discern their relative contributions to RM. The results are presented in Table 6. Demographic variables including caregiver age and education were entered into the first block to control for these variables. The first block was found to be not significant, $R^2 = .01, F(2, 53) = .37, p = .69$. For the second block, the predictor variable perceived stress was added to the analysis. The results revealed the model to be statistically significant with perceived stress accounting for an additional 8% of the variation in self-reported RM among caregivers, $\Delta R^2 = .08, F(1, 52) = 4.57, p = .04$. For the third block, the predictor variable burden was added to the

analysis. The results revealed the model to be not statistically significant with burden accounting for no additional variance in RM, $\Delta R^2 = .00$, $F(1, 51) = .00$, $p = .99$.

CHAPTER V

DISCUSSION

Caregivers are critical in helping persons with dementia live at home longer, but the caregiving experience is associated with increased risk of physical (Vitaliano et al., 2003; Son et al., 2007; Fonareva & Oken, 2014) and cognitive decline among caregivers (Pertle et al., 2015; Lathan et al., 2016; Vitaliano et al., 2017). The present study adds to the existing literature by examining the ways in which the Covid-19 pandemic could further affect this group of people. Consistent with hypotheses, stress was found to be positively associated with the extent to which the pandemic was disruptive to caregiver lives, frequency of prospective and retrospective memory mistakes among caregivers, and frequency of disruptive and depressive behaviors among care recipients. Results also indicated that caregiver burden was negatively associated with disaster preparedness. Contrary to prediction, stress was not found to be correlated with care recipient memory problems, and burden was not correlated with the number of available support services, the amount of time spent caregiving, or frequency of prospective and retrospective memory mistakes. These findings and their implications are discussed more fully in the following sections.

Factors Associated with Stress Among Caregivers

In the present study, stress was found to be positively associated with PRLD, meaning those who reported higher levels of stress also reported higher levels of reported disruption due to the pandemic. Having a set routine can be beneficial for both the caregiver and care recipient as it

helps maintain stability (Hibberd et al., 2009; Greenberg, et al., 2020). Unfortunately, the Covid-19 pandemic, like other natural disasters, disrupts one's daily routines and that disruption and change in everyday life has been shown to be related to an increase in care recipient problem behaviors (Christensen & Castaneda, 2014). This provides a likely reason for why disruption from the Covid-19 pandemic relates to stress among caregivers. Understanding the relationship between stress and pandemic-related life disruption is particularly important as past literature has documented the negative effects of stress on caregivers (Son et al., 2007; Correa et al., 2015; Lathan et al., 2016). The Covid-19 pandemic poses additional stress and strain for caregivers, potentially impacting their health and well-being. While work examining the effects of Covid-19 has just begun, some published work has examined certain parts of the change in caregiving that is occurring due to the pandemic. For example, research has found that caregivers report an increase in their own anxiety, depression, and distress since the onset of the pandemic (Cohen et al., 2020; Rainero et al., 2020; Zucca et al., 2021). Further, those who were more concerned about the Covid-19 pandemic had the greatest risk of experiencing overload from their caregiving demands (Savla et al., 2021). In research by Tam and colleagues (2021), caregivers attributed their heightened stress to difficulties associated with caring for their loved ones during the Covid-19 pandemic, further documenting the link between disruption and changes from the pandemic and stress. These findings along with ours emphasize that caregivers are facing added difficulties during the pandemic and that these challenges are associated with increases in self-reported stress.

Care recipient memory and behavior problems can be a source of added stress among caregivers as they increase the demands of caregiving tasks (Savla et al., 2011; Ornstein & Gaugler, 2012). Unexpectedly, stress among caregivers was not related to care recipient memory problems in our sample. This is surprising as other literature has found that caregivers reported a decline in care recipient cognitive function during the Covid-19 pandemic (Canevelli et al., 2020;

Rainero et al., 2020; Borelli et al., 2021). Further, worsening cognitive function is related to an increase in caregiver distress (Borelli et al., 2021), likely due to caregivers being required to provide more assistance with tasks that the care recipient may have been able to do themselves previously. While these studies examined how care recipient memory changed since the onset of the pandemic, the findings emphasize that changes and worsening in care recipient cognitive performance will likely add stress to caregivers as they must adjust to how they care for their loved ones. One possible reason the present study did not have similar results could be due to participants indicating DK responses more often on the Memory subscale than the other two subscales of the RMPBC. This may be because some care recipient memory problems (e.g., difficulty concentrating, trouble remembering recent events) are more ‘invisible’ making it difficult for caregivers to estimate their frequency.

In the present study, perceived stress among caregivers was positively associated with care recipient disruptive behaviors meaning that caregivers who reported higher levels of stress also reported higher frequency of disruptive behaviors among their care recipients. Recent work documents an increase in behavior problems among care recipients during the pandemic (Cohen et al., 2020; Rainero et al., 2020; Borelli et al., 2021), which may contribute to additional stress among caregivers. However, Cohen et al. (2020) found that behavioral problems were more prevalent among care recipients with mild dementia compared to those with more severe dementia, and Carbone et al. (2021) did not find any significant change in behavior problems, indicating the Covid-19 pandemic may impact care recipients differently based on their disease severity. While disruption to daily life is related to care recipient behavior problems (Christensen & Castaneda, 2014), other factors may also relate to behavior problems. Pickering et al. (2020) examined predictors of care recipient problem behaviors utilizing caregiver reports through a daily diary and found that caregiver stress significantly predicted behavior problems in the care recipient the next day. This finding indicates the complexity of the relationship between caregiver

stress and care recipient behavior problems and suggests the need to further examine how disruptive behaviors relate to caregiver stress.

The present study also documented that perceived stress among caregivers was positively related to care recipient depressive behaviors. This finding aligns with past literature demonstrating that care recipient depressive symptoms negatively impact caregiver well-being, burden, and depression (Ornstein & Gaugler, 2012). Additionally, caregiver stress is also related to care recipient depressive symptoms among caregivers of older adults more generally in addition to caregivers of PWD, indicating the relationship may be present among multiple types of caregivers (Ejem et al., 2015). Recent work since the onset of the Covid-19 pandemic has found caregivers report an increase in apathy, depressive symptoms, and loneliness among their care recipients (Borelli et al., 2021; Carbone et al., 2021). This further emphasizes the importance of understanding the relationship between care recipient behaviors and caregiver stress as not only are caregivers facing mental health decline, but their loved ones likely are as well.

Care recipient memory and behavior problems may serve as a potential stressor for caregivers as these behaviors may require additional caregiving demand. Examining the relationship between caregiver stress and care recipient memory and behavior problems is particularly important during the Covid-19 pandemic as the disruption to daily life may make these problematic behaviors worse. In the present sample, 46.4% of caregivers reported an increase in memory or behavior problems in their care recipient since the start of the Covid-19 pandemic, demonstrating that many caregivers are observing increased problem behaviors in their care recipients. This finding coupled with the significant relationship between stress and care recipient disruptive and depressive behaviors emphasizes the need to better understand this relationship as well as ways to reduce problematic behaviors among care recipients to potentially reduce caregiver stress.

Research examining ADCs has documented that ADC use can decrease behavioral problems among care recipients and decrease stress among caregivers (Liu et al. 2018; Zarit et al., 2011), indicating a possible intervention to help lower caregiver stress. Unfortunately, during the Covid-19 pandemic ADCs were not available for many caregivers that typically rely on them. Development and implementation of other interventions that decrease problematic behaviors is important for lowering stress among caregivers. For example, interventions that improve the relationship between the caregiver and care recipient and encourage skills and activities the care recipient can participate in can help reduce burden and care recipient problem behaviors (Rausch et al., 2017). Interventions that can be implemented at home by the caregivers themselves would likely be the most effective types within the context of a pandemic. One possible intervention for caregivers is practicing mindfulness meditation, which has been found to benefit caregivers and lower caregiver burden and stress (Hou et al., 2014; Tkatch, et al., 2017; Whitebird, et al., 2013). Further, research by Tkatch et al. (2017) saw reductions in caregiver burden, stress, and anxiety even when mindfulness training was implemented online, allowing caregiver attendance to be more flexible. Exploring interventions that can be done individually is an important step as many caregivers need flexibility in how they implement interventions. This is particularly useful during a health crisis like Covid-19 when caregivers may not be able to take advantage of interventions and resources that require face-to-face contact.

The present study further examined factors potentially contributing to stress by determining whether PRLD and burden were significant predictors of stress among caregivers. While PRLD was not technically a significant predictor of stress, it accounted for 7.3% of unique variance of stress. It is likely that PRLD did not reach significance due to small sample size, and it will be important to further examine this predictor of stress with a larger sample. Burden was found to be a significant predictor of stress among caregivers and accounted for 32.4% of variance over and above PRLD, further replicating the important relationship between stress and

burden (Zarit et al., 1980; Leggett et al., 2010). These findings allow for a better understanding of overall stress among caregivers during the Covid-19 pandemic and point to specific factors that could be targeted to prevent or reduce stress during future catastrophic events.

Factors Associated with Caregiver Burden

Similar to stress, burden also relates to caregivers' well-being and is an important aspect of determining areas for intervention. Contrary to what was predicted, burden was not found to be related to formal and informal support services. This is contrary to past literature indicating that support services, especially Adult Day Services, are important in lowering caregiver burden (Maseda et al., 2015; Ellen et al., 2017). The present study measured the amount of support services available during the pandemic, instead of the amount of support services utilized or whether the support services offered were helpful. It is possible that caregivers had many unhelpful support service options, or a small amount of very helpful support services. It is also possible that type of support service is an important consideration especially during this time. Zucca et al. (2021) found that while discontinuity in paid assistance was associated with higher stress among caregivers, availability of assistance was also associated with higher levels of anxiety and concern with contracting the Covid-19 virus. This could indicate that types of assistance that require face-to-face interaction are less beneficial during the pandemic.

Consistent with prediction, burden among caregivers was negatively related to caregivers' preparedness to care for their loved one during the Covid-19 pandemic. This demonstrates that caregivers who reported being more prepared for the Covid-19 pandemic also reported less burden. Literature exploring preparedness during the Covid-19 pandemic is very limited, but literature on past natural disasters provides relevant information on preparation among caregivers. During disaster, caregivers have unique challenges while preparing as they may have previously been able to rely on their care recipient to assist, but as their disease

progresses, caregivers may have to handle problems related to the care recipient resisting changes made for preparations or requiring additional help beyond what individuals without dementia would need (Christensen & Castaneda, 2014). Since past literature has also found that access to cooperation and assistance from others can be a barrier to older adults being better prepared (Kleier, et al., 2017), preparation could be particularly difficult for caregivers who are also older themselves and may not be getting assistance from others during the Covid-19 pandemic. Older adults were more likely to get information related to Covid-19 from more sources compared to younger adults, and those receiving information from multiple sources were more worried and took more protective actions (Chu et al., 2021). This could be beneficial as they may be better prepared, which can be especially important given the seriousness of older adults contracting Covid-19 (Dosa et al., 2020). Dosa and colleagues (2021) documented the importance for long-term care facilities to be prepared for Covid-19 given the higher risk of complications for older individuals especially those with comorbidities. This gives insight into the importance for caregivers of PWD to also be prepared as their care recipient faces many of the risks someone in a long-term care facility would face, such as age and comorbidities. Caregivers of PWD likely also face heightened risk as the present study found many caregivers to be older themselves. The current work extends literature on caregiver preparedness during natural disasters and the pandemic by providing information on how preparedness relates to feelings of burden among caregivers during a global health crisis.

Unexpectedly, the present study found that time spent caregiving was not significantly related to caregiver burden. The amount of time spent doing caregiving tasks has previously been found to be a predictor of burden (Chang et al., 2010; Kim et al., 2011). A possible reason that time spent caregiving was not related to burden in the present study could be due to the circumstances of the Covid-19 lockdown impacting responses to some survey questions. Some questions for the burden measure asked about the impact of caregiving on one's social life and

interactions with family and friends. These interactions were likely restricted by measures meant to slow the spread of Covid-19, and therefore caregivers may not attribute their lack of social interaction to their caregiving responsibilities during this time. While the present study did not find the amount time spent caregiving to be related to caregiver burden, it is important to further explore this particularly with a larger sample to see if the findings replicate. Since resources that may lower the amount of time spent doing caregiving related tasks are no longer available during the Covid-19 pandemic, it is important to fully explore how lack of services could impact caregiver burden.

Factors Associated with Self-reported Cognition

Once we established caregivers were experiencing stress and that for many this had increased since the start of the Covid-19 pandemic, we examined how stress was related to everyday memory behaviors that are essential to independent living. Results demonstrated that higher levels of self-reported stress among caregivers were related to greater frequency of self-reported prospective and retrospective memory mistakes. Contrary to hypotheses, self-reported prospective and retrospective memory mistakes were not related to burden. This may indicate that levels of stress, rather than levels of burden have a greater influence on caregivers' cognitive performance and potential decline. The findings are consistent with past literature that examined PM in other caregiver groups and found that caregivers of children with special healthcare needs had lower PM performance (Lovell et al., 2014; Lovell et al., 2019; McBean & Schlosnagle, 2016). Further, a hierarchical multiple regression identified stress as a significant predictor of self-reported frequency of PM mistakes, but not caregiver burden. The effect of stress on PM among noncaregivers is unclear. For example, past research examining younger and older adults in a laboratory-based PM study found that subjective stress and heart rate were not related to PM performance across the whole sample (Ihle et al., 2014). However, when comparing younger

adults and older adults on PM performance in a naturalistic study, Ihle and colleagues (2012) found that higher everyday stress was related to lower PM performance for both age groups.

It is important to further explore the relationship between caregiving and PM because this form of memory is particularly important for ensuring one's ability to live independently and needs to be intact for caregivers to care for their loved ones successfully. Woods et al. (2012) found that lower PM functioning was associated with minor problems with instrumental activities of daily living functioning, and Tierney et al. (2016) found that those with poorer activities of daily living functioning also had lower time-based PM functioning (e.g., taking medications at a specific time). These findings indicate that PM performance relates to one's ability to perform tasks that are necessary for one to live at home longer, highlighting the importance of understanding PM performance among caregivers who are likely older themselves. Since the present study found stress to be a predictor of self-reported PM mistakes, it is especially important to consider how stress may influence the relationship between PM and everyday activity functioning, especially among caregivers.

The significant positive correlation between stress and self-reported PM mistakes extends past literature that documents higher reports of stress being related to cognitive decline, including areas of RM functioning (Chen & Botticello, 2013; Pertle et al., 2015). In the present study, stress was found to be a significant predictor of RM mistakes and accounted for 8% unique variance in RM. However, burden did not significantly predict self-reported frequency of RM mistakes. Past literature has demonstrated that caregivers of PWD have lower RM performance compared to noncaregivers, and that cognitive performance was negatively associated with stress (Chen & Botticello, 2013; Pertle et al., 2015; Lathan et al., 2016; Bottiggi et al., 2017). RM functioning is an important indication of overall cognition. While past literature has already explored RM among caregivers of PWD (Bottiggi et al., 2017; Chen & Botticello, 2013; Pertle et al., 2015), the present study further examined RM subjectively and explored its relation to stress and burden.

The significant positive correlation between stress and self-reported RM mistakes further solidifies past findings of decline in retrospective functioning being related to stress. Overall, these findings demonstrate that stress is a key factor in self-reported frequency of forgetting among caregivers which could mean that it plays a role in the cognitive decline caregivers experience.

Better understanding the factors associated with stress and burden among caregivers provides information necessary to explore interventions and helps identify resources that caregivers need most. Caregivers provide a great deal of assistance to older adults who require it. With changes in the healthcare system, caregivers are even more critical to caring for older adults due to prescribed shorter hospital stays and higher requirements for at home treatment (Cohen & Eisdorfer, 2011). In fact, each year caregivers provide over \$300 billion worth of care to their loved ones, all unpaid (Cohen & Eisdorfer, 2011). This emphasizes just how frequently individuals require the assistance of caregivers and providing those caregivers the support they need is necessary to ensure the older adult population receives the care they need. While caregivers provide so much for individuals who need assistance, they often face many challenges from the experience. Those challenges likely increased during the Covid-19 pandemic much like with other natural disasters and times of high stress. The current findings indicate factors associated with stress are particularly relevant during and after the Covid-19 pandemic as it provides information on the struggles that this specific disaster is causing caregivers and helps us better understand what will be needed during the next one.

Limitations and Future Directions

One limitation of this study was the reliance upon self-report measures. Unfortunately, in-person data collection that would have allowed for objective stress or memory measures was not possible due to restrictions during the Covid-19 pandemic during the time this study was

conducted. However, this study provides new information on PM within this population and lays the foundation for future research to explore objective PM among caregivers. This is especially important as no prior work has examined PM performance among caregivers of PWD and very little has been done on other types of caregivers. The work that has examined other types of caregivers documents differences in PM performance among caregivers compared to noncaregivers, indicating a need to explore PM in other caregiver populations such as caregivers of PWD. There may be difficulties in conducting this research utilizing objective measures as this population may have difficulty finding time for in-person studies. This could be a contributing factor to the current gap in the literature on PM among caregivers of older adults and PWD. Nevertheless, the potential impact of the work is such that researchers should continue to attempt to examine PM performance among caregivers of PWD and other caregiving populations.

Another limitation of this study was that two of the measures, PRLD and preparedness, had low reliability. Both of these measures were created for this study in order to gain information about the Covid-19 pandemic. It is possible that this low reliability was due to both measures only consisting of five items each. Further research utilizing additional measures would assist in understanding how preparedness and PRLD may impact stress and burden among caregivers.

Understanding the factors associated with stress, burden, and cognition allows us to better understand how to assist caregivers. This is particularly important during the Covid-19 pandemic and similar natural disasters as caregivers face more challenges to care for their loved one such as lower resources, heightened care needs, and elevated stress and burden (Greenberg et al., 2020; Christensen & Castaneda, 2014). Understanding the impact of the Covid-19 pandemic is an important step in understanding what changes need to be made following this event. This research examined the areas that need the most intervention to assist this population giving insight into how the Covid-19 pandemic and similar disasters could impact caregivers. This study also gives

insight into the relationship between stress, burden, and cognition in a population that faces high chronic stress and burden not only during the Covid-19 pandemic, but during their typical daily lives as well.

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APPENDICES

Table 1*Caregiver Demographics*

	N = 56
Caregiver Age (in years), <i>M</i> (SD)	64.2 (12.49)
Care Recipient Age (in years), <i>M</i> (SD)	82.8 (7.79)
Caregiver Gender <i>n</i> (%)	
Male	6 (10.7)
Female	50 (89.3)
Care Recipient Gender <i>n</i> (%)	
Male	29 (51.8)
Female	26 (46.4)
Other	1 (1.8)
Relationship <i>n</i> (%)	
Spouse	20 (35.7)
Adult Child	31 (55.4)
Other Family Member	2 (3.6)
Friend	2 (3.6)
Other	1 (1.8)
Living with PWD <i>n</i> (%)	51 (91.1)
Marital Status <i>n</i> (%)	
Never Married	9 (16.1)
Married	39 (69.6)
Divorced/Separated	6 (10.7)
Widowed/Not Remarried	2 (3.6)
Time Spent Caregiving (hours per day) <i>M</i> (SD)	8.98 (6.8)
Education <i>n</i> (%)	
High School/GED or below	4 (7.1)
Vocational school/College	32 (57.2)
Graduate/professional school	20 (35.7)
Income <i>n</i> (%)	
Less than \$20,000	5 (8.9)
\$20,000 - \$40,000	6 (10.7)
\$40,000 - \$60,000	5 (8.9)
\$60,000 - \$80,000	10 (17.9)
\$80,000 - \$100,000	10 (17.9)
\$100,000 - \$200,000	12 (21.4)
Over \$200,000	3 (5.4)

Table 2*Descriptive Statistics and Correlations for Study Variables*

Variable	<i>n</i>	<i>M</i> (<i>SD</i>)	Range	1	2	3	4	5	6	7	8	9	10	11
1. Perceived Stress	56	19.25 (6.30)	0-31	-										
2. Burden	56	26.28 (7.10)	11-43	.62**	-									
3. Prospective Memory	56	18.59 (4.90)	8-32	.30*	.22	-								
4. Retrospective Memory	56	15.19 (4.68)	8-25	.27*	.14	.79**	-							
5. Pandemic-Related Life Disruption	56	19.70 (2.64)	13-24	.28*	.29*	.06	-	.06	-					
6. Care recipient Memory ^a	56	3.39 (.66)	1.6-4	.07	.15	.07	.00	.44**	-					
7. Care recipient Disruption ^a	56	.97 (.73)	0-4	.37**	.38**	.19	.16	.20	.25	-				
8. Care recipient Depression ^a	56	1.43 (.88)	0-4	.35**	.37**	-.04	.01	.10	.11	.28*	-			
9. Support Services	56	2.36 (1.53)	0-5	-.24	-.03	-.17	-	.15	.07	-.09	-.26	-.20	-	
10. Preparedness	56	20.48 (2.94)	14-25	-.27*	-.30*	-.09	-	.11	-.17	-.15	-	-.36**	-.42**	.07
11. Time Spent Caregiving	55	8.98 (6.80)	1-24	.00	-.04	.01	.12	.08	.31*	.20	-.26	-	.13	.14

^a Variable's average score utilized instead of total scores.

* $p < .05$. ** $p < .01$

Table 3*Perceptions of Pandemic-Related Life Disruption*

	Mean (SD)	Decreased a lot n (%)	Decreased a little n (%)	Stayed the same n (%)	Increased a little n (%)	Increased a lot n (%)
Time Spent Caregiving Burden	4.56 (.85)	1 (1.8)	-	7 (12.5)	12 (21.4)	36 (64.3)
Stress	4.20 (.77)	-	1 (1.8)	9 (16.1)	24 (42.9)	22 (39.3)
Care Recipient Behaviors	4.12 (.76)	-	1 (1.8)	10 (17.9)	26 (46.4)	19 (33.9)
Memory Mistakes	3.70 (.93)	1 (1.8)	-	29 (51.8)	11 (9.6)	15 (26.8)
	3.21 (.59)	-	3 (5.4)	40 (71.4)	11 (19.6)	2 (3.6)

Table 4*Hierarchical regression of pandemic-related life disruption and caregiver burden on perceived stress*

Step	Variable	<i>Std. β</i>	<i>b</i>	<i>t</i>	<i>p</i>
1	Demographic Variables, $R^2 = .01$				
	<i>Age</i>	-.07	-.04	-.51	.61
	<i>Education</i>	.07	.24	.47	.64
2	Pandemic-Related Life Disruption, $\Delta R^2 = .07$				
	<i>Pandemic-Related Life Disruption</i>	.27	.64	1.96	.06
3	Caregiver Burden, $\Delta R^2 = .32$				
	<i>Caregiver Burden</i>	.61	.54	5.27	< .001
Overall R^2 for Complete Model, $R^2 = .40$, $F(4, 51) = 8.61$, $p = <.001$					

Table 5*Hierarchical regression of perceived stress and caregiver burden on prospective memory*

Step	Variable	<i>Std. β</i>	<i>b</i>	<i>t</i>	<i>p</i>
1	Demographic Variables, $R^2 = .03$				
	<i>Age</i>	-.17	-.07	-1.25	.22
	<i>Education</i>	.04	.11	.28	.78
2	Perceived Stress, $\Delta R^2 = .08$				
	<i>Perceived Stress</i>	.29	.22	2.20	.03
3	Caregiver Burden, $\Delta R^2 = .00$				
	<i>Caregiver Burden</i>	.01	.00	.06	.95
Overall R^2 for Complete Model, $R^2 = .11$, $F(4, 51) = 1.65$, $p = .18$					

Table 6*Hierarchical regression of perceived stress and caregiver burden on retrospective memory*

Step	Variable	<i>Std. β</i>	<i>b</i>	<i>t</i>	<i>p</i>
1	Demographic Variables, $R^2 = .01$				
	<i>Age</i>	.09	.03	.64	.53
	<i>Education</i>	-.07	-.19	-.48	.63
2	Perceived Stress, $\Delta R^2 = .08$				
	<i>Perceived Stress</i>	.28	.21	2.14	.04
3	Caregiver Burden, $\Delta R^2 = .00$				
	<i>Caregiver Burden</i>	-.00	-.00	-.02	.99
Overall R^2 for Complete Model, $R^2 = .09$, $F(4, 51) = 1.31$, $p = .28$					

Appendix A

Summary of Measures			
Measure Name	Reference	Scoring	Scoring Range
Zarit Burden Interview	Zarit et al., 1980	0 (<i>never</i>) to 4 (<i>nearly always</i>)	0 to 48
Revised Memory and Behavior Problems Checklist	Teri et al., 1992	0 (<i>never occurred</i>) to 4 (<i>daily or more often</i>)	Disruption 0 to 32 Memory 0 to 28 Depression 0 to 36
Perceived Stress Scale	Cohen, Kamarak, & Mermelstein, 1983	0 (<i>never</i>) to 4 (<i>very often</i>)	0 to 40
Connor-Davidson Resilience Scale	Connor & Davidson, 2003	0 (<i>not at all true</i>) to 4 (<i>true nearly all of the time</i>)	0 to 100
Pandemic-Related Life Disruption	Items developed for the current study	1 (<i>they have decreased a lot</i>) to 5 (<i>they have increased a lot</i>)	5 to 25
Formal and Informal Support Services	Items developed for the current study	Sum total of number of support services	1 to 9
Covid-19 Preparedness	Items developed for the current study	1 (<i>not at all prepared</i>) to 5 (<i>extremely prepared</i>)	5 to 25
Prospective and Retrospective Memory Questionnaire	Smith et al., 2000	1 (<i>never</i>) to 5 (<i>very often</i>)	8 to 40 (for each subscale)

^a Connor-Davidson Resilience Scale will be given to participants for exploratory purposes, but there are no specific hypotheses.

Appendix B

Informed Consent

Agreeing to participate in “Impact of Covid-19 on Caregivers” indicates that you are willing to participate in the research being conducted by Rachael Turner and Dr. Celinda Reese-Melancon in the Department of Psychology at Oklahoma State University. It also indicates that you understand that this participation is entirely voluntary, and you can withdraw your consent at any time and have the results of the participation, to the extent that they can be identified as yours, removed from experimental record, or destroyed.

Please consider the following information before you agree to participate:

- 1) The purpose of this study is to better understand caregivers and the demands that are associated with caregiving tasks, particularly the demands during the Covid-19 pandemic.
- 2) You will be entered into a drawing as compensation for your participation within this study. The drawing will be for a \$25.00 gift card to either Wal-Mart, Target, or Amazon, and you will have a 1 in 25 chances of winning.
- 3) The procedures are as follows: You will be asked to fill out several questionnaires about yourself and the person you provide care for. Participation should take approximately 20 – 30 minutes of your time.
- 4) The risks, discomforts, or stresses that may be faced during this research: There is no risk, discomfort, or expected stress beyond that associated with answering questions about daily life.
- 5) The records of this study will be kept private. Any responses you provide will be confidential and will not be associated in any way with your name. Research records will be stored securely and only research and individuals responsible for research oversight will have access to the records. Electronic data sheets will be stored in password protected files.

If you have any questions about your participation in this research session you may email Rachael Turner (rachael.turner10@okstate.edu) or you may email Dr. Celinda Reese-Melancon (celinda.reese@okstate.edu). If you have questions about your rights as a research volunteer, you may contact the IRB Main Office, 223 Scott Hall, Stillwater, OK 74078, (405) 744-3377 or irb@okstate.edu.

Appendix C

Demographics Questionnaire

1. How would you rate your health at the present time?
 - a. Excellent
 - b. Good
 - c. Fair
 - d. Poor
2. How much do your own health troubles stand in the way of doing things you want to do?
 - a. Not at all
 - b. A little (some)
 - c. A lot
3. Do you think your health is better, the same as, or worse than most people your age?
 - a. Better
 - b. Same
 - c. Worse
4. Are you the primary caregiver of an adult?
 - a. Yes
 - b. No
5. Does anyone else provide a great deal of care/assistance to your loved one?
 - a. Yes
 - b. No
6. Who else provides a great deal of care/assistance to your loved one?
 - a. Your sibling
 - b. Your spouse
 - c. Loved one's spouse
 - d. Adult child
 - e. Other
7. What is your biological sex?
 - a. Male
 - b. Female
 - c. Prefer to self-describe
8. What is the biological sex of the person you provide care for?
 - a. Male
 - b. Female
 - c. Prefer to self-describe
9. How old are you? _____
10. How old is the person you provide care for? _____
11. What is your ethnic background (select all that apply):
 - a. White/Caucasian
 - b. Hispanic/Latino/Latina
 - c. Black/African American
 - d. Native American
 - e. Asian/Asian American
 - f. Other
 - g. Do not choose to indicate
12. What is your current marital status?
 - a. Never Married

- b. Married
 - c. Divorced or Separated
 - d. Widowed, not remarried
13. How many years of formal education have you completed? (e.g., 12 years = high school diploma, 13 years = some college/vocational training, 16 years = college graduate)
- a. 7 years or less
 - b. 8
 - c. 9
 - d. 10
 - e. 11
 - f. 12
 - g. 13
 - h. 14
 - i. 15
 - j. 16
 - k. 17 years or more
14. What has been your employment status prior to the Covid-19 pandemic?
- a. Employed full time
 - b. Employed part time
 - c. Retired
 - d. Unemployed
15. How has the Covid-19 pandemic impacted your employment? (select all that apply)
- a. Now work from home
 - b. No longer able to work
 - c. Deemed an essential employee
 - d. Deemed a nonessential employee
 - e. Work hours have increased
 - f. Work hours have decreased
 - g. No impact to employment
16. Have employment changes impacted your ability to care for your loved one?
- a. Yes
 - b. No
17. Has caregiving for your loved one impacted your ability to work since the Covid-19 pandemic started?
- a. Yes
 - b. No
18. What is your yearly household income?
- a. Less than \$20,000
 - b. \$20,000 – 40,000
 - c. \$40,000 – 60,000
 - d. \$60,000 – 80,000
 - e. \$80,000 – 100,000
 - f. \$100,000 – 200,000
 - g. Over \$200,000
19. Please select the state that you currently live in.
- a. Arkansas
 - b. Kansas
 - c. Louisiana
 - d. Missouri
 - e. New Mexico
 - f. Oklahoma

- g. Texas
- h. Other _____

Appendix D

Time Spent Caregiving

1. What is your relationship to the care recipient?
 - a. Spouse
 - b. Son of care recipient
 - c. Son-in-law of care recipient
 - d. Daughter of care recipient
 - e. Daughter-in-law of care recipient
 - f. Other family member
 - g. Friend
 - h. Other _____
2. What is the diagnosis of the person you provide care for? (select all that apply)
 - a. Alzheimer's or other Dementia
 - b. Developmental Disability
 - c. Physical Disability
 - d. Other _____
3. How long ago was your loved one diagnosed with Alzheimer's or other dementia?
 - a. Less than a month
 - b. 1 – 3 months
 - c. 4 – 6 months
 - d. 7 – 9 months
 - e. 10 – 12 months
 - f. 1 – 2 years
 - g. 3 – 5 years
 - h. 5 – 10 years
 - i. More than 10 years
4. How long have you spent caring for the person you provide care for?
 - a. Less than a month
 - b. 1 – 3 months
 - c. 4 – 6 months
 - d. 7 – 9 months
 - e. 10 – 12 months
 - f. 1 – 2 years
 - g. 3 – 5 years
 - h. Over 5 years
5. Do you live in the same household as the person you provide care for?
 - a. Yes
 - b. No
 - c. Other _____
6. What types of activities do you assist your loved one with? (select all that apply)
 - a. Eating
 - b. Bathing
 - c. Dressing
 - d. Toileting
 - e. Helping with medications
 - f. Communicating
 - g. Providing transportation

- h. Looking after one's appearance
 - i. Other _____
- 7. On average how many hours a day do you devote to caregiving tasks (e.g., feeding, dressing, bathing, transportation/outings, assisting with medications, etc.)?
 - a. 1 – 24 hours
- 8. How has the time you've spent doing caregiving related tasks changed since the Covid-19 pandemic started?
 - a. It has decreased a lot
 - b. It has decreased a little
 - c. It has stayed the same
 - d. It has increased a little
 - e. It has increased a lot

Appendix E

Zarit Burden Interview

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980)

Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001)

Please rate how often you feel the following questions are true for you in regard to the person you provide care for.

0	1	2	3	4
Never	Rarely	Sometimes	Quite Frequently	Nearly Always

1. Do you feel that because of the time you spend with your loved one that you don't have enough time for yourself?
2. Do you feel stressed between caring for your loved one and trying to meet other responsibilities (work/family)?
3. Do you feel angry when you are around your loved one?
4. Do you feel that your loved one currently affects your relationship with family members or friends in a negative way?
5. Do you feel strained when you are around your loved one?
6. Do you feel that your health has suffered because of your involvement with your loved one?
7. Do you feel that you don't have as much privacy as you would like because of your loved one?
8. Do you feel that your social life has suffered because you are caring for your loved one?
9. Do you feel that you have lost control of your life since your loved one's illness?
10. Do you feel uncertain about what to do about your loved one?
11. Do you feel you should be doing more for your loved one?
12. Do you feel you could do a better job in caring for your loved one?

Appendix F

Revised Memory and Behavior Problems Checklist

Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P. P. (1992)

The following is a list of problems care recipients sometimes have. Please indicate if any of these problems have occurred during the past week with the person you provide care for (the care recipient). If so, indicate how often the problems occur.

Measure typically includes caregivers' reaction rating to the items, but this was not included.

0	1	2	3	4	9
Never occurred	Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Don't know/not applicable

1. Asking the same question over and over. (M)
2. Trouble remembering recent events (e.g., items in the newspaper or on TV). (M)
3. Trouble remembering significant past events. (M)
4. Losing or misplacing things. (M)
5. Forgetting what day it is. (M)
6. Starting, but not finishing, things. (M)
7. Difficulty concentrating on a task. (M)
8. Destroying property. (Di)
9. Doing things that embarrass you. (Di)
10. Waking you or other family members up at night. (Di)
11. Talking loudly and rapidly. (Di)
12. Appears anxious or worried. (De)
13. Engaging in behavior that is potentially dangerous to self or others. (Di)
14. Threatens to hurt oneself. (De)
15. Threatens to hurt others. (Di)
16. Aggressive to others verbally. (Di)
17. Appears sad or depressed. (De)
18. Expressing feelings of hopelessness or sadness about the future (e.g., "Nothing worthwhile ever happens", "I never do anything right"). (De)
19. Crying and tearfulness. (De)
20. Commenting about death of self or others ("Life isn't worth living", "I'd be better off dead"). (De)
21. Talking about feeling lonely. (De)
22. Comments about feeling worthless or being a burden to others. (De)
23. Comments about feeling like a failure or about not having any worthwhile accomplishments in life. (De)
24. Arguing, irritability, and/or complaining. (Di)

* De indicates Depression subscale; Di indicates Disruption subscale; M indicates Memory subscale.

**Items 20 – 24 not included due to experimenter error

Appendix G

Perceived Stress Scale

Cohen, Kamarak, & Mermelstein (1983)

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate how often you thought or felt a certain way.

1	2	3	4	5
Never	Almost never	Sometimes	Fairly often	Very often

1. In the last month, how often have you been upset because of something that happened unexpectedly?
2. In the last month, how often have you felt that you were unable to control the important things in your life?
3. In the last month, how often have you felt nervous and “stressed”?
4. In the last month, how often have you felt confident about your ability to handle your personal problems?
5. In the last month, how often have you felt that things were going your way?
6. In the last month, how often have you found that you could not cope with all the things that you had to do?
7. In the last month, how often have you been able to control irritations in your life?
8. In the last month, how often have you felt that you were on top of things?
9. In the last month, how often have you been angered because of things that were outside of your control?
10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

Appendix H

Connor-Davidson Resilience Scale

Connor, K. M. & Davidson, J. R. T. (2003)

For the following list of items, rate how true you believe the item to be for you over the past month.

0	1	2	3	4
Not true at all	Rarely true	Sometimes true	Often true	True nearly all of the time

1. Able to adapt to change.
2. Have close and secure relationships.
3. Believe that sometimes fate or God can help.
4. Can deal with whatever comes. *
5. Past success gives confidence for new challenges.
6. See the humorous side of things.
7. Coping with stress strengthens me.
8. Tend to bounce back after illness or hardship.
9. Things happen for a reason.
10. Give best effort no matter what.
11. You can achieve your goals.
12. When things look hopeless, I don't give up.
13. I know where to turn for help.
14. Under pressure, I focus and think clearly.
15. Prefer to take the lead in problem solving.
16. Not easily discouraged by failure.
17. Think of self as a strong person.
18. Make unpopular or difficult decisions.
19. Can handle unpleasant feelings.
20. Have an act on a hunch.
21. Strong sense of purpose.
22. In control of your life.
23. I like challenges.
24. You work to attain your goals.
25. Pride in your achievements.

* Item 4 not included due to experimenter error

Appendix I

Modified Adult Day Service Process and Use Measure

Gaugler, J. E. & Dykes, K. (2019)

Please rate how much you agree or disagree with the following statements regarding your use of Adult Day Services prior to closures due to the Covid-19 pandemic.

* Utilized 5 items from the original 49-item measure, and modified them for use during the Covid-19 pandemic

1	2	3	4	5
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

1. Adult Day Services allows my relative to talk to other people/socialize.
2. I could benefit more from Adult Day Services if my relative used it more.
3. I wish I had used Adult Day Services earlier for my relative.
4. The relationships my relative has developed at Adult Day Services have benefitted him/her.
5. Even on days that my relative does not attend Adult Day Services, he/she can do some of the exercises or activities from Adult Day Services at home, which is helpful.

ADDITIONS:

1. Did you use Adult Day Services prior to the Covid-19 pandemic?
 - a. Yes
 - b. No
2. Prior to Covid-19, how often did you typically use Adult Day Services per week?
 - a. 1 day per week
 - b. 2 days per week
 - c. 3 days per week
 - d. 4 days per week
 - e. 5 days per week

3. Prior to Covid-19, how many hours, on average, did your loved one attend Adult Day Services on the days that they went?
 - a. 1 to 2 hours
 - b. 3 to 4 hours
 - c. 5 to 6 hours
 - d. 7 to 8 hours
4. What reason(s) did you use Adult Day Services? (select all that apply)
 - a. Need care while going to work
 - b. Need time for myself
 - c. Adult Day Service provides socialization for my loved one
 - d. My loved one was experiencing serious health problems, so it was necessary
 - e. My loved one was suffering behavior problems
 - f. Other _____
5. What do you miss MOST about Adult Day Services?
 - a. The activities/socialization provided for my loved one
 - b. Getting time for myself
 - c. Getting assistance so I could go to work
 - d. Assistance with health problems
 - e. Assistance with behavior problems
 - f. Other _____
6. Is your Adult Day Service offering any assistance during the closures?
 - a. Yes
 - b. No
7. What assistance is your Adult Day Services offering?
 - a. Online activities
 - b. At home activities
 - c. Information about resources
 - d. Phone calls to check in
 - e. Other _____
8. How likely are you to return to Adult Day Services once they reopened?
 - a. Very Unlikely
 - b. Unlikely
 - c. Neither likely/or unlikely
 - d. Likely
 - e. Very Likely

Appendix J

Pandemic-Related Life Disruption Questionnaire

Developed for this study

Please indicate how the item has changed for you since the Covid-19 pandemic started.

1	2	3	4	5
Decreased a lot	Decreased a little	Stayed the same	Increased a little	Increased a lot

1. How has the time you have spent doing caregiving related tasks changed since the Covid-19 pandemic started?
2. Have your feelings of strain from caregiving tasks changed since the Covid-19 pandemic started?
3. Have the behavioral or memory problems of the person you provide care for changed since the Covid-19 pandemic started?
4. How have your feelings of stress changed since the Covid-19 pandemic started?
5. How have your memory mistakes changed since the Covid-19 pandemic started?

Appendix K

Covid-19 Preparedness Questionnaire

Developed for this study

Answer the following items in regard to your present circumstances during the Covid-19 pandemic. Please rate your level of preparedness regarding you and your care recipient.

1	2	3	4	5
Not at all prepared				Extremely prepared

1. How prepared do you feel you are with food and similar supplies?
2. How prepared do you feel you are on your own medications and medical supplies?
3. How prepared do you feel you are on medications and medical supplies for the person you provide care for? *
4. How prepared do you feel you are to care for the person you provide care for? *
5. How prepared do you feel you are to keep your loved one, whom you normally provide care for, healthy? *
6. How prepared do you feel you are to ensure your loved one, whom you provide care for, practices social distancing? *
7. How prepared do you feel you are for someone else to take over caring responsibilities for your loved one if needed? *

* Indicates items specific to preparedness for the care recipient

ADDITION:

1. Is there anyone else prepared and capable of caring for the care recipient of you are unable (i.e., sick, working, self-quarantined)?
 - a. Yes
 - b. No
2. What resources do you have access to in order to assist in caring for your loved one? (select all that apply)
 - a. Family members or friends
 - b. Formal (paid) assistance
 - c. Online activities for loved ones
 - d. None
 - e. Other _____
3. Have you or a close loved one been directly affected by a Covid-19 diagnosis?
 - a. Yes
 - b. No

Appendix L

Prospective and Retrospective Memory Questionnaire

Smith, G., Della Sala, S., Logie, R. H., & Maylor, E. A. (2000)

The following questions pertain to memory mistakes that everyone makes from time to time. Because caregiving can be a challenging experience, we are interested in how it can impact the caregiver. Please select the response that represent how often each of these things happen to you.

1	2	3	4	5
Never	Rarely	Sometimes	Quite often	Very often

1. Do you decide to do something in a few minutes time and then forget to do it?
2. Do you fail to recognize a place you visited before?
3. Do you fail to do something you were supposed to do a few minutes later even though it's there in front of you, like take a pill or turn off the kettle?
4. Do you forget something that you were told a few minutes before?
5. Do you forget appointments if you are not prompted by a reminder such as a calendar or diary?
6. Do you fail to recognize a character in a radio or television show from scene to scene?
7. Do you forget to buy something you planned to buy, like a birthday card, even when you see the shop?
8. Do you fail to recall things that have happened to you in the last few days?
9. Do you repeat the same story to the same person on different occasions?
10. Do you intend to take something with you, before leaving a room or going out, but minutes later leave it behind, even though it's there in front of you?
11. Do you mislay (misplace) something that you have just put down, like a magazine or glasses?
12. Do you fail to mention or give something to a visitor that you were asked to pass on?
13. Do you look at something without realizing you have seen it moments before?
14. If you tried to contact a friend or relative who was out, would you forget to try again later?
15. Do you forget what you watched on television the previous day?
16. Do you forget to tell someone something you had meant to mention a few minutes ago?

Appendix M

IRB Approval

Oklahoma State University Institutional Review Board

Date: 04/27/2020
Application Number: IRB-20-234
Proposal Title: The impact of Covid-19 on caregivers
Principal Investigator: Rachael Turner
Co-Investigator(s): Erin Harrington
Faculty Adviser: Cindy Melancon
Project Coordinator:
Research Assistant(s):
Processed as: Exempt
Exempt Category:
Status Recommended by Reviewer(s): Approved

The IRB application referenced above has been approved. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in 45CFR46.

This study meets criteria in the Revised Common Rule, as well as, one or more of the circumstances for which continuing review is not required. As Principal Investigator of this research, you will be required to submit a status report to the IRB triennially.

The final versions of any recruitment, consent and assent documents bearing the IRB approval stamp are available for download from IRBManager. These are the versions that must be used during the study.

As Principal Investigator, it is your responsibility to do the following:

1. Conduct this study exactly as it has been approved. Any modifications to the research protocol must be approved by the IRB. Protocol modifications requiring approval may include changes to the title, PI, adviser, other research personnel, funding status or sponsor, subject population composition or size, recruitment, inclusion/exclusion criteria, research site, research procedures and consent/assent process or forms.
2. Submit a request for continuation if the study extends beyond the approval period. This continuation must receive IRB review and approval before the research can continue.
3. Report any unanticipated and/or adverse events to the IRB Office promptly.
4. Notify the IRB office when your research project is complete or when you are no longer affiliated with Oklahoma State University.

Please note that approved protocols are subject to monitoring by the IRB and that the IRB office has the authority to inspect research records associated with this protocol at any time. If you have questions about the IRB procedures or need any assistance from the Board, please contact the IRB Office at 405-744- 3377 or irb@okstate.edu.

Sincerely,
Oklahoma State University IRB

Appendix N

IRB Modification Approval

Oklahoma State University Institutional Review Board

Application Number: IRB-20-234
Proposal Title: The impact of Covid-19 on caregivers
Principal Investigator: Rachael Turner
Co-Investigator(s): Erin Harrington
Faculty Adviser: Cindy MelanconProject
Coordinator:
Research Assistant(s):
Status Recommended by Reviewer(s): Approved

Study Review Level: Exempt Modification Approval Date: 04/30/2020

The modification of the IRB application referenced above has been approved. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in section 45 CFR 46. The original expiration date of the protocol has not changed.

Modifications Approved:

Modifications Approved: Minor update to consent and add survey questions

The final versions of any recruitment, consent and assent documents bearing the IRB approval stamp are available for download from IRBManager. These are the versions that must be used during the study.

As Principal Investigator, it is your responsibility to do the following:

1. Conduct this study exactly as it has been approved.
2. Submit a status report to the IRB when requested
3. Promptly report to the IRB any harm experienced by a participant that is both unanticipated and related per IRB policy.
4. Maintain accurate and complete study records for evaluation by the OSU IRB and, if applicable, inspection by regulatory agencies and/or the study sponsor.
5. Notify the IRB office when your research project is complete or when you are no longer affiliated with Oklahoma State University.

Sincerely,

Oklahoma State University IRB
223 Scott Hall,
Stillwater, OK 74078

Website:

<https://irb.okstate.edu/>

Ph: 405-744-3377 | Fax: 405-744-4335 | irb@okstate.edu

VITA

Rachael Leigh Turner

Candidate for the Degree of

Master of Science

Thesis: FACTORS ASSOCIATED WITH CAREGIVER STRESS AND SELF-REPORTED COGNITION DURING THE COVID-19 PANDEMIC

Major Field: Psychology

Biographical:

Education:

Completed the requirements for the Master of Science in psychology at Oklahoma State University, Stillwater, Oklahoma in December, 2021.

Completed the requirements for the Bachelor of Arts in psychology at Washburn University, Topeka, Kansas in 2019.

Experience:

Graduate Assistant in the Memory and Cognitive Aging Laboratory at Oklahoma state University

Undergraduate Research Assistant in a Cognitive Psychology Laboratory at Washburn University

Professional Memberships: Gerontological Society of American, Psychonomic Society, Oklahoma Psychological Society