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Locus of Control, Mindfulness, and Perceived Caregiver Burden in Informal Caregivers of People With Dementia

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This is to certify that the doctoral dissertation by

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Abstract

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Dissertation Submitted in Partial Fulfillment

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Abstract

Adult informal caregivers play an essential role in the care of people with dementia living in the community. Adult informal caregivers may experience a host of negative psychological, emotional, and physical effects because of their roles as caregivers. The purpose of this quantitative correlational study was to investigate the influence of locus of control and mindfulness on the perceived caregiver burden experienced by adult informal caregivers of people with dementia, controlling for relevant sociodemographic characteristics. Social determination theory and social learning theory provided the theoretical foundation for this study. Variables were measured using the Caregiver Burden Inventory, Mindfulness Attention Awareness Scale, and Locus of Control Scale. Sampling of participants included 104 adult informal caregivers of people with dementia living in the community. Hierarchical multiple linear regression was employed to analyze the data. The results indicated that locus of control was not significantly associated with perceived caregiver burden. However, mindfulness was significantly associated with perceived caregiver burden. Results may be used for positive social change to address the psychosocial challenges experienced by adult informal caregivers caring for people with dementia.

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Dedication

This dissertation is dedicated to my immortal beloved husband and my beloved mommy. Your struggles are now over, but we embarked on our journey together. It was the road less traveled, and that made all the difference. I needed to lose myself to find myself.

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Thank you to everyone who has been with me on this journey, especially my brother, Nicko, for his unwavering support and encouragement and my sister, Ileana, whose voice is always in my head and who has the uncanny ability to make me laugh at myself when I am too much! Thank you to my nephew, Nicky, who always seemed to know the right time to phone to calm my fears and my anxiety. Thank you to Cheri who reminded me how proud she is of me. Thank you to my friends who love me despite myself. Thank you to my Chair Dr. Matthew Howren, for always pulling me out of the rabbit holes and placing me on terra firma. Thank you to Dr. Peggy Gallaher for her support and guidance. Thank you to my God for all His blessings and mercies. Finally, thank you, Daddy, for teaching me that with God, all things are possible.

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Chapter 1: Introduction to the Study

Informal caregivers are the main care providers for people with dementia age 65 years and older living at home (Lethin et al., 2017). Informal caregivers are defined as people who provide care without the benefit of formal training, and may be the spouse/partner, child, relative, other household member, friend, or neighbor of the person with dementia (Office of Economic Co-operation and Development, 2019). Informal caregiving may include assisting the care recipient with activities of daily living (ADL) that include bathing, toileting, dressing, personal hygiene and nutrition, as well as instrumental activities of daily living (IADL), which include financial decision making, scheduling medical appointments, and supervising other tasks (Alzheimer's Association and National Association for Caregiving, 2004). Informal caregivers provide an estimated 80% of the care required by people with dementia living at home (Alzheimer's Association, 2020). As the disease progresses, there is an increase in caregiving needs (Lethin et al., 2017). Current estimates for 2021 suggest that 16 million people in the United States provided more than 15.3 billion hours of unpaid care for family members with Alzheimer's disease and related dementias with an estimated value of more than $270 billion (Alzheimer's Association, 2021). Informal caregivers provide an essential service to the care recipient and add both social and economic value to society because these individuals relieve the burden on the U.S. health care system and provide care at a fraction of the cost compared to hospital-based or nursing facility care.

The burden placed on informal caregivers has increased since the beginning of the COVID-19 pandemic. In addition to known stressors associated with caregiving, specific stressors related to the pandemic and virus variants included uncertain and conflicting prognoses, reduced access to health care because of an overburdened health care system, shortages of resources, financial challenges, the imposition of unfamiliar public health mandates, and conflicting messages from health and government authorities about vaccine efficacy. These stressors may have contributed to widespread emotional distress and increased the risk of mental illness and psychological trauma on a global scale (Pfefferbaum & North, 2020). Public health emergencies may affect the health, safety, and the emotional well-being of individuals and communities (Pfefferbaum & North, 2020) resulting in emotional isolation, stigma, loss of livelihoods, jeopardized financial security, housing insufficiency, school closures, and reduced access to essential medical resources.

For adult informal caregivers, a public health emergency may add additional stress and promote psychological suffering beyond the stress and burden associated with the informal caregiving of a person with dementia. Research has demonstrated that caring for a person with dementia can affect a caregiver's physical and psychological health, resulting in poorer physical health and increased PCB (PCB; Pinquart & Sorenson, 2003). Since the World Health Organization's declaration of COVID-19 as a global pandemic, numerous studies investigated the additional perceptions of caregiver burden among informal caregivers (Budnick et al., 2021; MacLeod et al., 2021). Other studies have examined the impact of the pandemic on informal caregivers' quality of life (Rodrigues et al., 2021; Todorovic et al., 2020), psychoeducational methods to improve PCB (Ercoli et al., 2021), and factors that foster resiliency among informal caregivers (Archer et al., 2021; Patel, 2021); caregiving challenges during COVID-19 (S. A. Cohen et al., 2021; Kent et al., 2020; Russell et al., 2020).

Others have investigated nonpharmacological interventions for dementia-related caregiver burden using a meta-analysis of 30 studies (Williams et al., 2018) and a systematic review of the effects of mindfulness training for psychological stress in family caregivers of people with dementia (Z. Liu et al., 2017). However, no research has examined the influence, if any, of locus of control and mindfulness in relation to PCB among adult informal caregivers of people with dementia living in the community and in the aftermath of the COVID-19 pandemic. The present study contributed to the existing body of knowledge of PCB across three dimensions. First, it contributed to the scholarly community's understanding of PCB. Second, it enhanced the existing literature on factors associated with PCB. Finally, it provided a foundation for further investigation into the association between mindfulness and locus of control on PCB among adult informal caregivers of people with dementia living in the community.

The research has created an opportunity for future research into identifying and implementing effective interventions using mindfulness-based stress reduction (MBSR) and a better understanding of the influence, if any, that locus of control and mindfulness have on the PCB experienced by adult informal caregivers of people with dementia who are living on the community. This chapter provides a discussion of the background literature, problem statement, research questions and hypotheses, theoretical framework, nature of the study, definitions, assumptions, scope and delimitations, limitations, and significance of this research. A summary and introduction to the literature review and methodology are included at the end of this chapter.

Background

The literature suggested that numerous psychological, emotional, social, and environmental factors influence the PCB experienced by adult informal caregivers of people with dementia prior to and in the context of the COVID-19 global pandemic. Although people with dementia living at home may qualify for a broad range of formal health care services, accessing and using these services during a global health emergency can prove daunting to adult informal caregivers because of the scarcity of services and the complexity in navigating the health care system (Marit-Moholt et al., 2020). Further, even when respite care and in-home services are available, some adult informal caregivers choose not to avail themselves of these services (Marit-Moholt et al., 2020). This may be because of anticipatory guilt, anxiety associated with relinquishing the care of the person with dementia to someone other than a trusted family member (Gallego-Alberto et al., 2020), and the guilt of having violated a social norm related to caring for one’s family member (Gonyea et al., 2008). For adult informal caregivers of people with dementia, guilt has been proposed as a major factor in the development of distress and depression (Spillers et al., 2008) and a predictor of anxiety and depression among informal caregivers in general (Gallagher et al., 2008).

For decades, researchers have investigated numerous factors that impact the PCB experienced by adult informal caregivers of people with dementia. These factors include the level of impairment of older people with cognitive impairments (Ajay et al., 2017), stress and mental health among caregivers (Lim & Zebrack, 2004), differences in coping strategies (Navarta-Sanchez et al., 2016), psychosocial interventions to support the mental health of adult informal caregivers (Wiegelemann et al., 2021), mindfulness (Weisman de Mamani et al., 2018), and locus of control and self-efficacy (Band-Winterstein et al., 2019). For example, Park (2021) investigated the challenges faced by three groups of people at the commencement of the COVID-19 pandemic: noncaregivers, short-term caregivers, and long-term caregivers. Park suggested that the differences in the exacerbation of physical and mental health among these groups persisted, after accounting for demographic, socioeconomic, and prepandemic factors and were related to the pandemic lockdowns and greater adjustments in the demands of caregiving.

Similarly, S. A. Cohen et al. (2021) investigated the short-term effects of obligatory social isolation because of government-mandated lockdowns on adult informal caregivers of people with dementia in Argentina. Using a sample of family caregivers of people with Alzheimer’s disease, S. A. Cohen et al. found that mandatory confinement due to government-mandated lockdowns increased caregiver stress independent of dementia severity, but those caregivers who provided care for people with late-stage or severe dementia experienced greater caregiver stress and burden. Factors that increased stress and PCB included fear of contracting the disease and fear of spreading the disease while assisting care recipients with late-stage Alzheimer’s disease with ADL.

Cipolletta et al. (2021) explored the experience of family caregivers of people with dementia during the COVID-19 pandemic in Italy. Using a sample of adult-child informal caregivers of people with dementia, Cipolletta et al. conducted a qualitative study to determine to what extent the global health emergency affected caregivers' lives and care routines. Cipolletta et al. found four key themes: the caregiver's experience, the care recipient's experience, the relationship between the caregiver and care recipient, and an increase in the time required to carry out care routines. Further, an analysis of the data suggested that caregivers approached care in one of three manners: apprehensive, fatalistic, and mindful. This research suggests that mindfulness may influence the PCB experienced by caregivers during a global health emergency.

Other studies have explored the psychological impact of the COVID-19 pandemic and lockdowns on caregivers of people with dementia and the roles that resiliency and self-efficacy played in influencing PCB (Polenick et al., 2020). Various coping strategies have been studied as predictors of perceived role overload during the stay-at-home phase of the pandemic (Savla et al., 2021). Collins and Kishita (2019) conducted a meta-analysis to investigate the effectiveness of mindfulness-based interventions for patients with mild cognitive impairment or dementia and their caregivers. In an examination of 12 studies of varying designs that conformed with Collins and Kishita's criteria, findings indicated that mindfulness- and acceptance-based interventions including MBSR (Kabat-Zinn, 1990) had a moderate effect on reducing burden in caregivers of people with dementia pre-to-post intervention. Collins and Kishita cautioned, however, that a significant limitation of the study was the quality of the studies that were analyzed and that the studies analyzed included small sample sizes and questionable data on the diagnoses of the care recipients and the diagnostic criteria used to determine the cognitive status of the care recipient.

Georgescu et al. (2019) explored the relationship between locus of control and personal behavior in the context of resilience. Georgescu et al. discussed the context of resilience as a host of predictive factors including genetic factors, engaging in prosocial behaviors (altruism), optimism, active coping style, cognitive flexibility (cognitive restructuring of negative thoughts), mindfulness, an internal system of values (healthy beliefs and values), and locus of control. Several hypotheses were proposed including that there is an association between internal locus of control, self-efficacy, and negative resilience. Results suggested that self-efficacy was negatively correlated with external orientation, leading Georgescu et al. to conclude that self-efficacy is related to an individual’s efforts and inner direction (internal locus of control). Although the results provided further evidence of the relationship between self-efficacy and internal locus of control in the general population, no studies had examined the role that locus of control may play in mitigating PCB among informal caregivers of people with dementia living in the community.

Collectively, these studies supported the need to examine the influence, if any, of mindfulness and locus of control on PCB. Current study findings may provide researchers, the scholarly community, and practitioners with information to assist them in more fully understanding the impact of the COVID-19 pandemic on informal caregivers of people with dementia and create appropriate and effective interventions to meet the informal caregiver’s needs to mitigate PCB. A need existed to investigate the influence of locus of control and mindfulness to modify cognitive reactions to caregiver’s stress and burden to improve the quality of life and physical well-being of adult informal caregivers.

Problem Statement

Adult informal caregivers of people with dementia experience elevated levels of stress and PCB (Connors et al., 2019; Chiao et al., 2015; Grau et al., 2015). Some researchers, scholars, and practitioners have offered strategies and interventions to mitigate PCB, while others have investigated the factors that influence PCB (Huang et al., 2015; Iavarone et al., 2014; Ruisoto et al., 2020; Tan et al., 2021). Others have investigated the impact of the COVID-19 pandemic on PCB and have concluded that numerous factors, both psychological and contextual, influence the PCB experienced by adult informal caregivers of people with dementia (Alves et al., 2021; Connors et al., 2019; Costello et al., 2020; Ercoli et al., 2021; Marroquin et al., 2020). Although some researchers recommended resources and strategies to mitigate PCB in the context of the COVID-19 pandemic (Patel, 2021), no research had considered the influence of locus of control and mindfulness on the PCB experienced by adult informal caregivers of people with dementia living in the community.

PCB among adult informal caregivers of people with dementia may result in physical and psychological health challenges (Braungart Fauth et al., 2016; Karg et al., 2018; Pinquart & Sorenson, 2003; Vitaliano et al., 1991; Vitaliano et al., 2003), and the COVID-19 pandemic exacerbated these health challenges (Bergmann & Wagner, 2021; Biliunaite et al., 2022; Lorenz-Dant & Comas-Herrera, 2021; Zucca et al., 2021). In the United States, approximately 53 million people provided unpaid care to an adult age 50 or older in 2020, and 21% of informal caregivers provided unpaid care to an adult with health or functional needs (National Alliance for Caregiving and AARP, 2020). Estimates of people aged 65 years and older living with Alzheimer’s disease or related dementia are 6.2 million (Alzheimer’s Association, 2021), and 1 in 3 seniors dies from Alzheimer’s or another dementia (Alzheimer’s Association, 2021). Three in 10 adult informal caregivers of people with dementia provide caregiving without outside assistance (paid or unpaid; Alzheimer’s Association, 2021). Further, adult informal caregivers of people with dementia expend on average 34.7 hours per week caregiving when the care recipient lives in the home with the adult informal caregiver (National Alliance for Caregiving and AARP, 2020).

There was an abundance of literature on the impact of the COVID-19 pandemic on adult informal caregivers of people with dementia (Boutoleau-Bretonniere, 2020a; Boutoleau-Bretonniere, 2020b; Greaney et al., 2021; Lorenz-Dant & Comas-Herrera, 2021; McLennon et al., 2021; Ortelli et al., 2021), but research had not focused on the influence of mindfulness and locus of control on the PCB experienced by adult informal caregivers of people with dementia living in the community. Mindfulness was chosen as a predictor variable for the present study because its benefits had been well-documented in several empirical studies and were found to be positively correlated with overall improvements in psychological functioning (Baer, 2003; Dalrymple & Herbert, 2007; Kabat-Zinn, 1982, 1990; Linnehan, 1993a, 1993b). Mindfulness had also been shown to mitigate PCB (Leyland et al., 2018), and the effectiveness of mindfulness and acceptance-based interventions for informal caregivers of people with dementia had been demonstrated in a meta-analysis of the literature (Collins & Kishita, 2019).

Locus of control was chosen as a predictor variable because studies had shown it to have important implications for improvements in overall psychological functioning (see Judge & Bono, 2001) and the stability and associations between parent and child locus of control expectancies (Nowicki et al., 2018). Further, studies had investigated changes over time in locus of control among people with dementia (Halse et al., 2021). For example, caregivers who possess an internal locus of control believe that external events can be influenced by their efforts, thoughts, and affect toward the events and resulting behaviors (Southwick & Charney, 2012). These factors, taken together, may mitigate or prevent stress-related disorders (Georgescu et al., 2019). Although these factors had been associated with improved caregiver well-being, it was not known whether mindfulness and locus of control influence the PCB experienced by adult informal caregivers of people with dementia living in the community. I sought to address this gap by examining the influence, if any, of mindfulness and locus of control on the PCB experienced by adult informal caregivers of people with dementia living in the community.

Purpose of the Study

The primary objective of this quantitative study was to examine the influence, if any, of mindfulness and locus of control on the PCB experienced by adult informal caregivers of people with dementia living in the community. Mindfulness (Kabat-Zinn, 1982, 1993; Kabat-Zinn & Burney, 1981) is grounded in social determination theory (SDT; Deci & Ryan, 1980; Ryan, 1995), and locus of control (Rotter, 1954, 1966) is grounded in social learning theory (Bandura, 1971, 1977, 1994). Bandura (1969, as cited in Grusec, 1992) theorized that individuals operate cognitively on their social experience, and it is within the realm of these operations that an individual’s behaviors and development are influenced. The findings from the current study may assist scholars, researchers, practitioners, and organizations in developing and implementing effective interventions to mitigate PCB and improve the quality of life of adult informal caregivers and their care recipients.

The instruments used to measure the independent variables for this research were the Mindfulness Attention Awareness Scale (MAAS; Brown & Ryan, 2003a) and the Locus of Control Scale (Rotter, 1966). The dependent variable was PCB, which was measured using the Caregiver Burden Inventory (CBI; Novak & Guest, 1989). PCB was operationally defined as the level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time (Z. Liu et al., 2020). The statistical methods used to test the predictive relationship between the independent variables and the dependent variable was hierarchical multiple linear regression analysis.

Research Questions and Hypothesis

The following research question (RQ) and hypotheses guided this study:

RQ1: What are the combined ($R2$) and relative ($sr2$) effects of locus of control and mindfulness in explaining variance in perceived caregiver burden, controlling for relevant sociodemographic characteristics?

H_o1: Locus of control and mindfulness do not explain variance in perceived caregiver burden, controlling for relevant sociodemographic characteristics.

H_a1: Locus of control and mindfulness explain variance in perceived caregiver burden, controlling for relevant sociodemographic characteristics.

Theoretical Framework

Mindfulness was examined through the lens of SDT (see Schultz & Deci, 2015) and is considered an essential element for the integrated regulation of behavior and autonomous self-regulation. Brown and Ryan (2003b) theorized that mindfulness is a synthesis of the internal and external awareness of the present moment that allows individuals to become aware of what is occurring within the self and the environment around them to make purposeful decisions. Mindfulness is conceptualized as an open awareness to both internal (e.g., psychological and somatic experiences) and external events as they occur. Mindfulness is a nonjudgmental awareness of the present moment. Although some studies have investigated the role of mindfulness in reducing the stress associated with the COVID-19 pandemic (Hall et al., 2020), these studies examined the effect of the pandemic on a specific population (e.g., patients with cancer, health care personnel, patients with Parkinson's disease; Heath et al., 2020; Kubo, et al., 2021; Kwon et al., 2020; Kwon & Lee 2021; Sivasubramoney & Lekshmy, 2020; van der Heide et al., 2020) or the general population (Antonova et al., 2021; Hartstone & Medvedev, 2021; Widha et al., 2021). No studies had investigated the influence of mindfulness on the PCB experienced by adult informal caregivers of people with dementia living in the community.

Rotter's (1966) conceptualization of locus of control suggests that an individual believes that rewards are dependent on their own behavior. Conversely, people who possess an external locus of control orientation believe that rewards are controlled by external forces and that their lives are determined by luck, chance, or fate (Rotter, 1966). Numerous studies have investigated a locus of control orientation in patient and adult populations (Boyd & Wilcox, 2017; Kesavayuth et al., 2020; Mercer et al., 2018) demonstrating that locus of control is associated with multiple important health outcomes, but no studies had investigated the association between locus of control and the PCB experienced by adult informal caregivers of people with dementia living in the community.

Nature of the Study

In this quantitative correlational study, I sought to examine the influence, if any, of mindfulness and locus of control on the PCB experienced by adult informal caregivers of people with dementia living in the community. This research was aligned with the multidimensional nature of PCB and the patterns of association between the five dimensions of burden (time, dependence, developmental, social, and emotional burden) as measured by the CBI (Novak & Guest, 1989) and selected sociodemographic indicators. In addition to the CBI (Novak & Guest, 1989), I used Rotter's (1966) LOCS and the MAAS (Brown & Ryan, 2003a). The LOCS is a 29-item questionnaire that measures the participant's level of internal-external control. The CBI is composed of 24 closed-ended questions divided into five dimensions: time-dependence, developmental, physical, social, and emotional burden. MAAS is a 15-item scale used to assess core characteristics of dispositional mindfulness. The IBM Statistical Package for the Social

Sciences (SPSS) Version 28 statistical software program was used to conduct the data analysis.

Definitions

Adult informal caregivers: Adult informal caregivers are any relative, partner, friend, or neighbor who has a significant personal relationship with and provides a broad range of assistance to a person or adult with a chronic or disabling condition (Family Caregiving Alliance, 2022). These caregivers have not been formally trained to provide care in the home, and any training they may have undergone was voluntary. More often, caregivers have no training and rely on previous experience, publicly available information, and the care recipient’s physicians for guidance and information.

Care recipients: Any individual who receives care for a medical condition or who requires support with ADL (National Alliance for Caregiving and AARP, 2009) and may require assistance with IADL (Holman & Loring, 2000).

Dementia: Dementia is a syndrome that results from a variety of diseases and injuries that primarily or secondarily affect the brain, such as Alzheimer’s disease or stroke (World Health Organization, 2021). Dementia is usually chronic or progressive in nature, which leads to a deterioration in cognitive function and affects memory, thinking, comprehension, learning capacity, language, motor skills, and judgment (World Health Organization, 2021).

Locus of control (LOC): LOC refers to how much control an individual believes they have over their actions as opposed to events in life occurring because of external forces. A person can have either an internal locus of control or an external locus of control (Rotter, 1954). Individuals who possess an internal locus of control believe that they control their behavioral outcomes, and people who possess an external locus of control believe that situations are controlled by fate or external forces. Rotter (1966) suggested that locus of control or personal control was best explained as the degree to which a person develops an expectancy that their behavior is associated with either external or internal reinforcements.

Mindfulness: Mindfulness means paying attention in a particular way, on purpose, in the present moment, and nonjudgmentally (Kabat-Zinn, 1991). Brown and Ryan (2003b, 2004) expanded on the definition to include an open and receptive awareness of what is occurring in the present moment.

Perceived caregiver burden (PCB): PCB is the perception of stress and fatigue caused by the sustained effort required in caring for people with chronic illness or other conditions with special needs (Caregiver burden. (n.d.) TheFreeDictionary.com. (2023)).

Assumptions

I assumed that all participants would answer the questions truthfully and to the best of their ability, and that all participants would be unbiased in their responses. I also assumed that all responses would be analyzed accurately for purposes of generalizability. Further, I assumed that caregiving is a stressful experience and caregivers experience varying degrees of PCB that have an adverse effect on their physiological and psychological well-being. A final assumption was that not all informal caregivers experience the negative consequences often associated with caregiving.

Scope and Delimitations

The results of this study may provide insights into the influence, if any, of mindfulness and locus of control on the PCB experienced by adult informal caregivers of people with dementia living in the community. The insights from this study may assist scholars, researchers, and practitioners in identifying the influence of mindfulness and locus of control on the PCB experienced by adult informal caregivers of people with dementia living in the community as well as designing and implementing effective strategies to mitigate PCB among this segment of the population. As the need for in-home care increases, adult informal caregivers will assume greater responsibility for the care of people with dementia and other cognitive declines such as Parkinson's disease and Alzheimer's (Family Caregiving Alliance, 2022). The physiological and psychological well-being of adult informal caregivers will become a greater social and economic priority (Gallagher et al., 2011b; Grabel & Adabbo, 2011).

This study included a cross-section of adults 18 years of age and older were informal caregivers to people with dementia. People with other chronic conditions were excluded from this study, as were formal, paid, or professional caregivers. The results of this study may be generalized to individuals who provide care to people with cognitive declines and frail older people. Health care professionals, policymakers, and health care administrators may find the findings from this research beneficial when considering policies related to informal caregivers of people with dementia and related cognitive impairments and how a global pandemic impacts informal caregivers generally.

Limitations

Due to the focus on participants who are adult informal caregivers of people with dementia, the results may not be generalizable to a larger caregiving population. A second limitation is the contextual factor of the aftermath of the COVID-19 pandemic, which may have influenced the responses of the participants. The results may not be generalizable to caregivers since COVID-19 became an endemic health issue. Further, all measures, including those used in this study, rely on the self-report recollections and may have included a measure of inherent bias and inaccurate recollections of previous events and experiences.

Significance

These results of this research may be significant because a growing portion of the population in the United States includes adult informal caregivers of people with dementia. The results of the study may be significant in several ways. First, the findings may expand how scholar-practitioners perceive mindfulness and locus of control and the influence of these factors on the overall psychological well-being of adult informal caregivers. Second, the results may add to the current body of knowledge on the influence of PCB on both adult informal caregivers and care recipients. Finally, researchers and scholar-practitioners may gain insights into the influence of locus of control and mindfulness on the PCB experienced by adult informal caregivers of people with dementia in the aftermath of the COVID-19 pandemic.

At the time of this research, no studies had addressed the influence, if any, of mindfulness and locus of control on the PCB experienced by adult informal caregivers of people with dementia living in the community in the aftermath of the COVID-19 pandemic. The study's findings may promote a more thorough and holistic understanding of the PCB experienced by adult informal caregivers in the aftermath of a global health emergency. Findings may also lead to more effective interventions using an evidence-based approach to mindfulness training and increasing an individual's locus of control to mitigate PCB among this segment of the population.

Summary

PCB is a multidimensional, dynamic process made more complex by the global pandemic. The sudden onset of COVID-19 and fear of contracting the disease can have profound effects on the mental health of adult informal caregivers and care recipients (Mirzaei et al., 2020). Further, contracting COVID-19 can disrupt the lives of the care recipient and adult informal caregivers and affect the social and familial relationships (Arnout et al., 2020; Borges-Machado et al, 2020; S. Liu et al, 2017; Pongan et al., 2021). The current endemic served as an important context for further study of PCB in adult informal caregivers of people with dementia (see Mirzaei et al., 2020).

Although numerous studies investigated the positive and negative aspects of caregiving generally and in the context of the COVID-19 pandemic, research had not addressed the influence of mindfulness and locus of control on the PCB experienced by adult informal caregivers of people with dementia living in the community in the aftermath of the pandemic. This research may enhance the understanding of caregiver burden and foster the development of interventions using mindfulness and locus of control techniques to decrease caregiver burden, improve the mental health of adult informal caregivers, and foster a more positive overall caregiving experience, thereby increasing the quality of life for adult informal caregivers and care recipients. In Chapter 2, I review the peer-reviewed literature on caregiving and dementia generally and caregiving in the context of the global pandemic. The theoretical foundations and their relevance for understanding PCB are also discussed.

Chapter 2: Literature Review

Adult informal caregivers of people with dementia face numerous challenges and may experience a host of negative physical and psychological outcomes including stress, depression, anxiety, and somatic problems (Duncan & Anderson-Hanley, 1998; W. E. Haley & Pardo, 1989; E. E. Haley & Perkins, 2004; Proulx & Snyder, 2009; Pinquart & Sorenson, 2007). These caregivers are considered a special at-risk segment of the caregiving population, whose caregiving responsibilities are dissimilar to their paid caregiving counterparts. Informal caregiving may involve changes in the care recipient's ability to engage in ADL and IADL (Edwards & Scheetz, 2002). Because of this, adult informal caregivers may need to learn new tasks and balance competing family and work demands, all while maintaining their own health and well-being. As these responsibilities mount, PCB may increase. PCB is defined as the physical, psychological, emotional, social, and financial problems that caregivers may experience while caring for impaired older adults (Yu et al., 2015). PCB has been associated with numerous negative outcomes such as perceived stress, depression, muscle strain, hypertension, and cardiovascular disease (Pinquart & Sorenson, 2003; Schulz & Sherwood, 2008; Shaw et al., 1997; Vitaliano et al., 2003).

The COVID-19 pandemic and its current endemic status may have exacerbated caregiving challenges and has resulted in major impacts on employment, financial well-being, social relationships, and the physical and mental health of caregivers, care recipients, and noncaregiving family members. Research suggested that there are specific stressors related to the COVID-19 pandemic, including fear of infection, disruptions in daily care routines, and lack of reliable information on the origins of the virus, vaccination safety, and efficacy. Chesak (2020) suggested that the COVID-19 pandemic placed more people in the United States in the role of unpaid caregiver, increasing the demands for those who were already assisting a loved one with daily tasks. Lockdowns, forced isolation, limited respite care, inaccessibility to adult daycare programs, and reduced access to in-person medical assistance may severely impact the overall physical and psychological well-being of adult informal caregivers as well as the care recipients (Chesak, 2020). Adult informal caregivers may experience a heightened sense of responsibility in addition to anxiety, fear, and depression, resulting in both physical and psychological deterioration. However, the long-term and distal effects of the COVID-19 pandemic and government-mandated lockdowns on adult informal caregivers of people with dementia had not been fully investigated. Certain psychological factors may help buffer against these negative impacts on caregivers. Previous research demonstrated that factors such as locus of control and mindfulness are associated with positive health outcomes, including one's ability to demonstrate resilience during difficult times (Georgescu et al., 2019).

Literature Search Strategy

Current peer-reviewed literature was investigated using the Walden University online library and Google Scholar. Inquiry terms specific to this study included *perceived caregiver burden, protective factors, mental health distress, dementia, lockdowns, locus of control, COVID-19 lockdowns, isolation, stigmas related to contracting COVID, family support*, and *isolation*. Using these search terms and variations of the terms ensured saturation of the literature. Databases included EbscoHost, PSYC Articles, Directory of Open Access, SAGE Journals, PubMed, ProQuest Central, Research Gate, and Google Scholar for open-access articles.

Review of Research Literature and Concepts

PCB

PCB is the stress associated with caregiving tasks, including time spent on ADL and IADL, and the caregiver's time and resources (Pavalko, 2011; Savundranayagam et al., 2011). Informal caregiving is considered a source of chronic stress and is a dynamic experience in which changes in the care recipient's status influence the intensity of the caregiver's stress and perceived burden (Lyons et al., 2015). Hong and Harrington (2016) investigated the negative health outcomes of PCB including chronic diseases such as heart disease and high blood pressure, somatic symptoms including sleep deprivation, and back and muscle pain. The quality of the relationship between a caregiver and a care recipient was the most predictive factor of the intensity of the caregiver's perceived feelings of burden.

Andren and Elmstal (2008) used a cross-sectional design to examine the association between PCB, perceived caregiver health, and the sense of coherence in family caregivers of people with dementia living at home. The sample included family caregivers and the relative with dementia for whom they provided care. Findings indicated that higher self-reports of PCB were positively correlated with the care recipient's severity of dementia and disease progression and the care recipients' level of dependency. Andren and Elmstal also found that higher levels of PCB were closely related to the caregivers’ and care recipients’ familial relationship and that distant relatives self-reported lower PCB. The higher level of burden the caregivers reported was related to the closeness felt by the caregiver and care recipient. An important finding was that the relationship between PCB and perceived health was influenced by the coping strategies employed by the caregiver and the caregiver’s sense of coherence or the ability to adapt to and manage the tasks associated with caregiving. Caregivers with a strong sense of coherence perceived problems as challenges rather than misfortune. Other findings suggested that higher PCB was positively associated with isolation, disappointment, and emotional involvement in the perceived health of the care recipient.

At the time of the current study, the influence of mindfulness and locus of control on PCB in the aftermath of the COVID-19 pandemic was largely unknown. Research implications existed for examining the influence of mindfulness and locus of control on PCB. Chapter 2 includes a review of the literature related to caregiving and the pandemic.

COVID-19 Pandemic and PCB

Li et al. (2021) postulated that caregivers would experience greater psychological and somatic problems because of the COVID-19 pandemic and subsequent lockdowns. The sample comprised caregivers of people with neurocognitive disorders in China. Participants included family caregivers and nursing home staff who participated in a cross-sectional survey to determine the prevalence of anxiety, depression, and sleep problems. Li et al. hypothesized that caregivers of older adults would experience dual stress related to the caregiving experience and the COVID-19 pandemic. Li et al. assessed anxiety, sleep disturbances, community-level infection contact, access to infection related information, medical and psychological history, and sociodemographic data. Analysis of the data suggested that caregivers with preexisting mental health conditions and those who were female reported an increased number of somatic and psychological symptoms at the beginning of the pandemic. Further, females who experienced community-level contact with a person with the virus and those with preexisting mental health conditions were at an increased the risk for depression. Li et al. found that community-level COVID-19 contact and being female were independent risk factors for experiencing multiple mental health problems.

In comparison to caregivers without preexisting mental health issues, caregivers with preexisting mental health conditions exhibited greater risk of multimorbidity (Li et al., 2021). Caregivers who obtained access to more positive health information exhibited a decreased risk for multimorbidity. Self-reported rates of anxiety and depression were higher than the rates reported from the general population but similar to health care workers who had been exposed to COVID-19. Overall, most participants reported higher levels of anxiety, depression, and sleep disturbances because of the pandemic, irrespective of chronic mental health issues and gender, and ascribed the higher levels of anxiety and depression to the contextual factors of the pandemic. Higher education may facilitate access to accurate information about COVID-19; however, Li et al. noted that the ability to obtain accurate pandemic-related information may increase fear because of the information being misinterpreted or misunderstood.

These results substantiate prior research that investigated whether gender differences accounted for disparities in psychological and somatic symptoms self-reported by caregivers, and whether those caregivers with chronic mental health issues prior to a global health emergency were at increased risk to experience anxiety related to the contextual factors of a global health emergency, including lockdowns, social distancing, and the inability to access accurate information. These findings suggest that caregivers experienced increased burden because of the COVID-19 pandemic, and for caregivers with prepandemic mental health issues, the pandemic exacerbated feelings of burden and placed these people at higher risk for multimorbidity.

Several lessons can be learned from Li et al.'s (2021) study. First, PCB influences caregiver outcomes during a pandemic. The COVID-19 pandemic and subsequent mandated lockdowns affected PCB as much as the resulting behaviors themselves, and the findings of this study underscored the importance of approaching PCB from a strengths perspective and the necessity to investigate whether PCB may be influenced by locus of control and mindfulness.

Adding to the body of knowledge on the effects of the pandemic on PCB and the role that gender may play in influencing PCB, S. A. Cohen et al. (2021) explored the changes in PCB and caregiving intensity during the COVID-19 pandemic. Of particular interest was whether caregivers experienced increased caregiver burden and caregiving intensity because of the increased challenges and changes to the type of caregiving provided, and in the intensity of caregiving, as well as changes in PCB (S.A. Cohen et al., 2021) because of the pandemic. In this context, caregiver burden included increased anxiety and depression, government-mandated stay-at-home orders, and the inability to access in-person medical attention. The sample participants included caregivers who cared for people with chronic medical conditions including dementia, heart disease, diabetes and hypertension. S. A. Cohen et al. differentiated between care recipients who resided with the caregiver, those who lived independently, and those who resided in assisted living or nursing facilities. An analysis of the data indicated that because of the pandemic, caregivers who self-reported an increase in PCB also experienced higher caregiving intensity compared to those who self-reported no change in caregiver burden. S. A. Cohen et al. noted that caregivers who reported an increase in caregiving intensity were more likely to have been diagnosed with COVID-19 (57%) compared to those who had not (43%).

Further analysis of the data suggested that gender influenced PCB and caregiving intensity, with males reporting lower caregiver burden and caregiving intensity; however, how contracting COVID-19 affected both PCB and caregiving intensity was less clear (S. A. Cohen et al., 2021). The overall results suggested that disparities in PCB and caregiving intensity in this population may be influenced in part, by gender Like the results of previous studies, the results of S. A. Cohen et al.'s (2021) study indicated that the COVID-19 pandemic negatively impacted the overall well-being of caregivers and resulted in increased PCB.

Additionally, Todorovic et al. (2020) investigated the effects of the pandemic on caregiver quality of life (QoL) among caregivers in Serbia. These authors employed a cross-sectional study using both qualitative and quantitative methods to assess changes in caregiver quality of life, changes in caregiver perceived physical health and changes in caregiving tasks because of the pandemic, using self-report assessments. A sample of informal caregivers participated in focus groups and self-health and the health of the care recipient were related to changes in the mental health of caregivers. The authors concluded that informal caregivers experienced negative physical and mental health outcomes because of the pandemic. The results provided further evidence that caregivers' experience changes in PCB because of the pandemic and it is not known whether protective factors such as mindfulness and locus of control may mitigate increased PCB.

Park (2021) investigated the differences in the mental and physical health of three groups of caregivers in the United States: noncaregivers, short-term caregivers) less than one year) and long-term caregivers (greater than one year) at the beginning of the COVID-19 pandemic. Secondary data obtained from the Understanding America Study was analyzed to determine group differences in psychological symptoms and physical health. This author suggested that the differences in the mental and physical health among these groups persisted after accounting for demographic, socioeconomic and pre-pandemic factors. Further, this author posited that the exacerbation of differences in mental and physical health were directly related to the effects of pandemic lockdowns, the demands of caregiving in general and greater adjustments in the demands of caregiving because of the pandemic.

Park found the overall proportions of poorer health during the pandemic for long-term caregivers was greatest amongst these three groups. Psychological distress was higher among long-term caregivers compared to their short-term counterparts. Expressions of somatic symptoms were greater among long-term caregivers compared to noncaregivers. The author assessed psychological distress, with a particular focus on depression and anxiety in relation to long-term caregivers' necessity to provide more intensive care for longer versus the rates of depression and anxiety amongst short-term and noncaregivers. The results of this study evidenced that long-term caregiving and changes in caregiving tasks because of the pandemic and government mandated lockdowns increased PCB. Results of these studies demonstrate the extent of the association between PCB and the ongoing COVID-19 pandemic. Further, these studies substantiate the need for further investigation into whether LOC and mindfulness influence PCB during a global health emergency.

Another study investigating changes in psychological symptoms amongst caregivers because of the COVID-19 pandemic was conducted by Altieri & Santangelo (2021). These authors investigated changes in psychological symptoms among caregivers because of the impact of the COVID-19 pandemic, subsequent lockdowns, and the effects of resiliency on participants in Italy. The authors utilized several methods to assess depressive symptoms, anxiety, PCB and resilience. Accounting for sociodemographic factors and obtaining clinical information for people with dementia, the researchers studied the effects of resiliency as a mitigating factor on caregiver burden, anxiety, and depression.

Participants completed an online survey and self-reported psychological symptoms experienced both pre-pandemic and during the pandemic. The authors concluded that low social support and higher dependence on the caregiver by the care recipient because of the pandemic resulted in an increase in anxiety, irrespective of resilience. The authors posited that while resilience was a protective factor against depressive symptoms and anxiety under normal circumstances, resilience may not serve as a protective factor under extraordinary factors such as a global pandemic.

An analysis of the data evidenced that during lockdowns, people high in resilience self-reported lower depressive unchanged compared to people scoring high in resilience. Further, for people low in resilience and whose care recipient experienced higher functioning dependence, the caregiver self-reported higher levels of PCB. The results showed that people high in resilience pre-pandemic reported higher levels of anxiety during lockdowns. The results of this study provide further evidence of the deleterious effects of the pandemic on PCB, irrespective of protective factors such as resilience, and this study suggests that resilience, considered a protective factor that mitigates caregiver burden, may in fact, result in higher levels of anxiety because of the effects of the pandemic.

Carballo et al. (2021) sought to analyze the relationship between fear and post-traumatic stress symptoms (PTSS) among the general population in Spain during the COVID-19 pandemic, using informal caregiving as a moderator variable. The study sample included men and women with 16.5% of the sample self-identifying as informal caregivers. Analysis of the data evidenced that people who self-identified as informal caregivers reported greater post-traumatic stress symptoms and fear, compared to their non-caregiving counterparts. Fear related to COVID-19 was a general theme in the analysis. The authors found that while many of the participants expressed a fear of the virus or contracting the virus, individuals who were informal caregivers expressed increased fear of the virus and contracting COVID-19, concerns over the duration of the lockdowns and greater severity of post-traumatic stress syndrome. These results suggested that informal caregivers are at an increased risk of PCB, post-traumatic stress and heightened fear during a pandemic compared to the general population.

Kent et al. (2020) provided an analysis of the current caregiving crisis in the context of the pandemic. The authors refer to current research on the unintended consequences of pandemic lockdowns, social distancing requirements and the inability to access routine in-person medical appointments and health screenings.

It has been well-established that since the onset of the pandemic, caregivers, and the people they care for, much like the public, have been unable to access routine medical care. Telehealth and telemedicine, designed to temporarily replace in-person appointments, cannot adequately address the necessity of annual health screenings or provide the essential medical services for people with chronic medical conditions, the elderly and those with life threatening diseases. Social isolation and depression among caregivers were further exacerbated by the ongoing pandemic and variants of the virus that appear to be more easily transmitted from person-to-person. These authors suggested that under ordinary circumstances, caregivers were not inclined to seek assistance in caring for a family member with dementia, Alzheimer’s, or other cognitive impairment.

People with dementia may be at higher risk for abuse from people without a familial relationship. The person being cared for may be unable to adequately verbalize mistreatment thereby increasing the caregiver’s anticipatory guilt over asking for help. During the recent pandemic, this type of emotional burden may be exacerbated by fear that outside people may place the person with dementia at an increased risk of contracting and succumbing to the virus.

The authors provided several suggestions for enhancing support services available to informal caregivers to mitigate the adverse psychological and health consequences of caregiving during the pandemic by providing personal protection equipment to caregivers, implementing thorough risk assessment questionnaires, encouraging. caregivers to seek assistance from family members to share the burden of caregiving and discussing the extraordinary circumstances of caregiving in COVID. These measures may offer an opportunity to better educate caregivers on how to navigate telehealth and allay the caregiver's concerns regarding keeping appointments for annual screenings, examinations and life-saving treatments. This study suggests that social distancing and mandated lockdowns increase fear and PCB among caregivers and that telehealth appointments and lack of in-person medical assistance increase depression and anxiety among this segment of the population.

Vaitheswaran et al. (2020) investigated the effects of the pandemic on PCB by examining the emotional well-being of caregivers. These authors specifically noted that the emotional well-being of the caregiver was influenced by the caregiver's concerns over self-hospitalization, the perceived stigma attached to contracting the virus and protecting the care recipient from contracting COVID-19. The authors employed a purposive sampling and utilized qualitative methods using semi-structured telephone interviews of caregivers of people with dementia in India. A thematic analysis of the data showed specific issues faced by the caregivers. The results indicated that caregivers exhibited greater PCB because of their fears associated with contracting the virus, caregiver uncertainty over how the care recipient would be cared for if the caregiver contracted the virus and protecting the care recipient against contracting COVID. The results suggested that fear and the stigma surrounding contracting the virus by both the caregiver and care recipient were integrally related to the level of PCB experienced by the caregivers.

The results of these studies demonstrate the extent of the association between PCB experienced by informal caregivers and the COVID-19 pandemic. Further these studies substantiate the need for investigation into whether mindfulness and locus of control influence PCB during or in the aftermath of a global pandemic.

Resilience, Mindfulness, and Locus of Control on PCB

Resilience

Resilience is a multidimensional construct that explains why people facing adversity and stress can engage in behaviors that result in positive outcomes (Palacio et al. 2020). People who are high in resilience emphasize adjusting their behaviors and attitudes towards experiences that are perceived as threatening (Palacio et al., 2020). Caregiving for people with dementia can be a source of stress for the caregiver, however, despite this, caregiving is not entirely a negative experience (Senturk et al., 2018). Senturk et al. (2018) posited that the positive affect and thoughts of caregivers of people with dementia despite the challenges may be associated with their high psychological resilience. Resilience has been considered both a personality trait and a skill (Oshio et al., 2018) and numerous studies have shown that resilience was negatively correlated with neuroticism. Still other studies showed significant relationships between resilience and personality (Oshio et al., 2018).

Altieri & Santangelo (2021) focused on the role that resilience played in mitigating perceived caregiver anxiety in the context of the psychological impact of the pandemic and government mandated lockdowns in 2020. The authors employed pre-lockdown and in-lockdown self-report measures designed to assess changes in the psychological symptoms of PCB of adult informal caregivers of people with dementia in Italy. Participants completed an online survey which included sociodemographic questions, clinical information about the person with dementia, the caregiver's relationship to the care recipient, the caregiver's habits, and lifestyle changes experienced by caregivers during lockdowns.

The researchers obtained information on both the caregiver's and care recipient's COVID status and all participants reported that neither they or the care recipients had contracted COVID, and that none of the participants were experiencing symptoms related to the virus. After corrections for multiple comparisons and a repeated measures multivariate analysis, the results revealed significant relationships between time and resilience scores, time and depressive symptoms and time and anxiety. Included in the measures was a subset of questions specific to anxiety. The questionnaire was deployed at two intervals, where participants self-reported depressive symptoms and feelings of anxiety experienced before the lockdowns and during the lockdowns thereby allowing for an analysis and comparison of levels of anxiety and depression among the caregivers both pre- and in-lockdowns.

Additionally, a between-group analysis was employed on caregivers of people with dementia and non-Alzheimer's caregivers to determine between-group differences in levels of depression and anxiety both before and during lockdowns, resilience levels, and PCB. The results evidenced no between-group difference in depression, anxiety, resilience, and caregiver burden and psychological changes among caregivers of older people, irrespective of a dementia diagnosis, are associated with government-mandated lockdowns, social distancing, limitations on individual mobility, and the lack of social support. Further, the authors discussed government findings that indicated increased levels of depression and anxiety among the general population during the lockdowns but noted that the results of the study confirmed an increase in depressive symptoms but not anxiety among adult informal caregivers of people with dementia.

The authors attributed the differences between the sample of participants and the general population to the small sample size. Additionally, results of the study showed that caregivers with high resilience levels exhibited lower levels of depression and anxiety before lockdown compared to caregivers with lower resilience levels. Conversely, caregivers with high resilience reported higher levels of anxiety compared to caregivers with lower levels of resilience who reported no significant changes in anxiety. The authors considered the possibility that high resilience, while considered a protective factor against depression and anxiety among caregivers under normal circumstances may not have the same effect on caregivers during extraordinary circumstances such as a global pandemic. Further, the pandemic may abrogate the advantages of having high resilience. The research showed that there was no evidence that dementia as a diagnosis among the care recipients influenced the psychological symptoms and burden experienced by caregivers of people with dementia compared to caregivers of people without a dementia diagnosis.

Despite negative aspects, the experience of caring for a loved one with dementia is not entirely negative (Senturk et al., 2018). The results of this study suggested that caregivers high in resilience find meaning in their caregiving tasks; that their personal development and commitment to the care recipient have increased, that caregivers have embarked on a journey not only to provide care for a loved one but also on a journey of self-discovery, and caregivers envision the experience as an opportunity to reconnect with the care recipient. While numerous studies have investigated the influence of resilience on PCB, no studies to date have investigated how mindfulness and locus of control may influence PCB during or after a global pandemic.

Duran-Gomez et al. (2020) studied the effects of resiliency on caregivers of people with Alzheimer’s disease in Spain. Adult informal caregivers of people with dementia and their care recipients were included in the cross-sectional design. Measures were utilized to assess care recipient’s dependency level, level of cognitive decline, neuropsychiatric and behavioral symptoms, and sociodemographic data from all participants.

Caregiver anxiety, depression, level of PCB, self-esteem, coping, social support, severity of somatic symptoms, health-related quality of life and resilience were measured, and the data analyzed. The authors hypothesized that the factors of high self-esteem or sense of competence, good health-related quality of life, and high levels of resilience would mediate PCB and lessen mental health distress including depression and anxiety. An analysis of the data revealed that caregivers who obtained the highest scores in certain dimensions of resilience, such as feeling in control of one’s life, thoughts and behaviors and an acceptance of change in the care recipient’s disease progression and health scored lower in PCB, depression, and anxiety. The subjective perception of greater burden was associated with lower resilience, a negative self-image, lower self-efficacy, a lower health-related quality of life, and poorer coping strategies to deal with stressful events. The researchers discovered significant differences in the negative repercussions of caregiving on the emotional well-being of the caregiver. The results demonstrated a dynamic relationship between higher levels of resilience and lower somatic symptoms experienced by the caregiver including decreased depressive symptomology and anxiety. The authors noted that resilience can be viewed as either a feature of personality or a set of behaviors, beliefs and learned actions accumulated throughout the lifespan that may be nurtured to manifest into appropriate emotional connections and positive affect toward stressful situations related to caregiving tasks and duration. Resilience, these authors posited, could be considered a significant predictor of the caregiver’s perceived health-related quality of life.

The results of this study showed that the positive affect of caregivers of people with dementia; despite the constant challenges of caregiving, may be associated with high psychological resilience. Resilience is considered an integral component of locus of control, and while numerous studies have investigated the role that resilience plays in mitigating PCB no studies have investigated the role that locus of control plays in reducing PCB.

Locus of Control

Locus of control refers to the extent to which individuals feel that they have control over the events that influence their lives. Gerrig & Zimbardo (2002) defined a locus of control orientation as an individual's belief about whether the outcomes of action are contingent on what we do (internal locus of control) or rely on event outside of our personal control (external locus of control). Rotter (1954) theorized that human behavior was controlled by rewards and punishments, and the consequences of our actions assist to determine our beliefs about the likely results of future behaviors (Rotter, 1966). People who possess an internal locus of control take responsibility for their actions and the resulting outcomes, while people with an external locus of control blame outside forces for their circumstances and credit luck or chance for any success they may experience (Cherry, 2021).

Contador et al. (2017) examined whether grounded optimism and external locus of control influenced dementia caregiver decision making relative to care settings prior to the pandemic among participants in Spain. Participants were recruited from an Alzheimer's organization and assessed for depression, caregiver burden, and perceived locus of control. The main measure outcome pertained to the care setting (in-home verses daycare centers) for the care recipient at baseline. The researchers sought to determine whether grounded optimism and locus of control influenced the decision making of caregivers when deciding whether to place the care recipient in adult daycare. In this study, placement in adult day care was considered a tool to reduce caregiving related stress and restore caregiver well-being. Participants who volunteered met certain inclusion criteria and prior use of daycare was the basis of exclusion after other inclusion criteria had been met. Caregivers who had applied for daycare center services but who had yet to receive services were placed in one group and participants who had initially chosen to defer the care recipient's placement in adult daycare were grouped in a second cohort. The aims of the study were: (1) to determine whether participants whose care recipient had yet to be placed in daycare scored significantly higher on external locus of control than those who provided care in the home; (2) to determine which group scored higher on PCB and depression; and (3) which group scored higher on grounded optimism because of their decision.

The results of the study showed that people who chose in-home care scored lower in depression and burden as compared to the daycare group. Further, the home care group scored significantly higher in grounded optimism than the daycare group. The results also indicated that the dimensions of grounded optimism (self-efficacy, contingency and success) were negatively related to burden and depression. The daycare group scored significantly higher on external locus of control and exhibited greater depressive symptomology than the home care group. The results of this study suggested that caregivers who possess a high internal locus of control are better able to cope with the circumstances of providing care and are less inclined to utilize community services. Caregivers who possess higher external locus of control are more inclined to utilize community services earlier and more often in their caregiving experience. Further, the study showed a positive correlation between length of time as a caregiver and grounded optimism and that time creates an opportunity for a caregiver to adapt to stressful situations and interpret external events more positively; thereby increasing grounded optimism. By examining locus of control in caregivers we will better understand if locus of control contributes to the caregiver's ability to withstand the difficulties involved in caregiving until the death of the care recipient.

Correspondingly, Band-Winterstein et al. (2019) assessed levels of depression and the proposed nexus between depression and care recipients' and caregivers' characteristics among Ultra-Orthodox Jewish primary caregivers in Israel. The participants were evaluated for depression and caregiver characteristics including self-rated health. Personality trait assessments of the caregivers included measures to assess locus of control and self-efficacy. A measure of care recipient frailty as perceived by the caregiver was also collected. Situational characteristics were ascertained using the caregivers' self-reported perceptions of social support.

The authors found higher levels of depression among participants in this study. The authors suggested that these levels may be explained by the caregiving dynamic present in the Ultra-Orthodox Jewish community, where caregiving is considered a duty and where failure is not an option. The authors found a significant association between depression and the caregiver's characteristics. There was a smaller but still significant association between the caregiver's personality characteristics [external locus of control (chance)] and self-efficacy. In this study, the authors found that the participant's sense of external locus of control emerged as the strongest predictor of depression, however self-efficacy was not predictive of depression. The authors suggested that Ultra-Orthodox Judaism places a high value on the concept of filial responsibility. This is in accordance with strict adherence to the fifth commandment to honor thy father and mother. According to these authors, Ultra-Orthodox Jews consider caregiving a divine test of faith and a responsibility for which the individual has no choice. The findings of this study suggested that the religious practices inherent in Ultra-Orthodox Judaism, considered external forces, promote a reduced sense of control and is predictive of adverse mental health outcomes among its practitioners. The results demonstrated the importance of examining the role of locus of control in the overall psychological well-being of caregivers. The authors recommended that intervention programs focused on caregivers' characteristics, specifically on the caregiver's perceived locus of control to promote an increased internal locus of control while adhering to the tenets of the caregiver's Ultra-Orthodox Jewish faith. Considering the buffering effects of locus of control on the lives of caregivers who practice ultra-orthodox Judaism, by extrapolation, it appears that locus of control may serve as a protective factor in the lives of caregivers of people with dementia in their sometime demanding journey during a global health emergency.

Mindfulness

Hsieh et al. (2019) sought to identify the mediating effects of mindfulness, self-compassion, compassion from others and patient's dispositional mindfulness on the relationship between caregiver stress and depression. The researchers examined the influence of these factors as mitigators of mental health distress and depressive symptomology. The sample included patients diagnosed with small cell lung cancer and their family caregivers. Several measures were employed to assess depression, dispositional mindfulness, and caregiver stress. While the study was conducted prior to the global pandemic, the researchers found that the protective factors of dispositional mindfulness, self-compassion and perceived compassion from others mediated the severity of mental health distress including depression. The researchers controlled for patient factors including severity of illness. Measures were used to determine the caregiver's and care recipient's severity of depressive symptoms, self-perceived caregiver health status, self-compassion, perceived compassion from others and dispositional mindfulness. A separate instrument was used to measure the different sources of caregiver stress and was repeated over time to assess changes in caregiver stress. Care recipients also completed a questionnaire designed to measure quality of life and level of functioning.

The results of the study indicated that caregiver stress was positively correlated with caregiver depressive symptoms, care recipients' severity of illness, care recipient's perceived health status and the care recipient's ability to engage in ADLs. Caregiver stress was negatively correlated with the care recipient's dispositional mindfulness. Caregiver stress was significantly associated with depressive symptoms. Caregiver mindful awareness and actions that promoted self-compassion significantly reduced perceived caregiver stress and depressive symptoms.

Mindful awareness or self-compassion were predictive of caregiver depressive symptoms. A further analysis of both mindfulness and self-compassion were tested together, and only self-compassionate actions remained as having a significant moderating effect on caregiver stress. The study also found that facets of caregiver dispositional mindfulness including acting with awareness of the present moment reduced automatic behavioral responses to negative events, reduced intrusive and ruminative thoughts, enhanced cognitive flexibility, and decreased maladaptive thoughts and actions.

Likewise, Weisman de Mamani et al. (2018) investigated the interplay between mindfulness, PCB, and mental health distress among family caregivers of people with dementia. A sample of family caregivers of people with dementia was utilized to assess the association among caregiver objective and subjective burden, mindfulness, mental health (depression and anxiety), and quality of life. The researchers hypothesized that lower levels of PCB and greater mindfulness would be positively associated with better mental health; that subjective burden would mediate the relationship between objective burden and mental health; and, that mindfulness would moderate the association between subjective burden (perceived feelings of burden and affect) and objective burden (financial strain and limitations on social functioning) among family caregivers of people with dementia living with the care recipient in a community setting. The authors further posited that a subjective appraisal of burden among caregivers would play an intermediary role in the association between the tangible costs of caregiving and the psychological outcomes in dementia care recipients.

Sociodemographic information was collected from caregivers and care recipients. Data regarding care recipient’s level of cognitive functioning, symptom severity, and confirmation of dementia diagnosis was collected through semi-structured interviews.

Caregiver mindfulness was assessed to determine the relationship between dispositional mindfulness and mental health. The results supported the researchers' hypothesis that greater mindfulness was associated with greater mental health. However, the hypothesis that mindfulness would moderate the relationship between PCB and mental health remained unsupported by the data. The researchers found a significant positive relationship between objective burden and mental health. An analysis of the data revealed a significant relationship between subjective burden and objective burden, and taken together, the influence of these combined factors on poorer mental health outcomes. While there is a plethora of research on the role that mindfulness plays in PCB, no studies to date have investigated how mindfulness may influence PCB as experienced by adult informal caregivers of people with dementia living in the community.

Theoretical Framework

Social Determination Theory and Mindfulness

Social determination theory (SDT) is a macro theory of human motivation that addresses issues within the realm of personality development, universal psychological needs, life goals and objectives, nonconscious thought processes, and the impact of culture and social environments on motivation, affect, behavior and well-being (Deci & Ryan, 2008) and that the type of motivation that underpins behavior may have a significant impact on psychological, physiological, and emotional well-being. Initially framed in the 1970s (Deci, 1971, 1975), its formal conceptualization began in 1985 with Deci & Ryan. SDT has been applied to explain differences in personality development, health care, sports, education, and professional achievement. Social determination theory suggests that awareness is a critical component of self-regulation and well-being (Deci & Ryan, 1980; Ryan et al., 2008). According to Deci & Ryan (2000) SDT is an empirically driven theory of human motivation and development that suggests that individuals are naturally curious, growth-oriented and seek to be active participants in and with their environment and strive to attain an equilibrium between a unified sense of self and the social framework within which they live. According to Ryan (1995, 2005) individuals seek challenges, pursue interests and social connectedness. The integration of a unified sense of self within a social context offers an individual the opportunity to become more fully actualized and experience a eudemonic lifestyle or one that is not influenced by external factors (Ryan, Huta et al., 2008; Ryan et al., 2013). Schultz and Deci (2015) differentiate SDT from other types of theories of motivation by positing that only through self-reflection and awareness is an individual able to fully recognize their needs and values and align these constructs with authentic feelings rather than a perception of how their behaviors should be. These authors suggest that mindfulness is an essential element for the integrated regulation of behavior and autonomous extrinsic self-regulation. Brown and Ryan (2003) stated that mindfulness, is a synthesis of the internal and external awareness of the present moment, that allows the individual to become aware of what is occurring within the self and the environment around them and to make purposeful decisions.

Mindfulness within the context of social determination theory is conceptualized as open awareness to both internal (e.g., psychological, and somatic experiences) and external events as they occur. It is a non-judgmental awareness of the present moment.

Mindfulness is construed as the ability to capture a meaningful existence and attain a satisfying life (Brown & Ryan, 2003). Mindfulness creates an opportunity to engage in self-reflection and consider how an individual's actions are in line with their personal values and needs and to act in a manner that is consistent with their authentic self (Schultz, n.d.). Schultz and Ryan (2015) suggest that the psychological processes associated with awareness impact both the content and quality of the individuals' extrinsic and intrinsic goals. Ryan et al. (2013) suggested that a person's psychological processes associated with awareness impact both the content and quality of the individual's extrinsic and intrinsic goals. Ryan et al. (2013) posited that persons who engage in acting autonomously while pursuing intrinsic goals can live eudaemonically, with the rich positive experiences associated with living well. Mindfulness is described as a state in which a person's ideal self and actual experience are very similar, and where the ideal self is consistent with actual behavior and in accordance with self-image. This, according to Brown & Ryan (2003) leads to a greater autonomy and a balance between the individual's intrinsic and extrinsic motivations for engaging in behaviors. Ryan &

Deci (2017) proposed that by exercising greater mindfulness, individuals become more aware of internal factors such as affect, impulses and needs, as well as external conditions or contextual factors such as social pressures and are better able to engage in reflective decision making and actions in line with the true self. Levesque& Brown (2007) found that persons who engage in mindfulness are more autonomously motivated to pursue actions in line with their personal values and needs. A central principle of SDT is that human motivation varies in amount, quality and level of personal autonomy (Deci

& Ryan, 1985; Ryan & Deci, 2017). Specific to social determination theory is the concept that motivations differ, and each type of motivation is of a specific character and as such, its own classification. Ryan & Deci (2000) posit that intrinsic motivation is the most autonomous, in that the individual possesses the capacity to make informed and uncoerced decisions without the anticipation of external rewards. Mindfulness, according to Wang et al. (2017) was associated with less materialism, and persons who engage in dispositional mindfulness are less concerned with external rewards (i.e., social status and wealth accumulation). Weinstein et al. (2009) found that mindful individuals can openly accept both pleasant and unpleasant experiences and integrate these experiences into their sense of self, which promotes psychological well-being.

Donald et al. (2020) conducted research using a systematic review of 89 relevant studies of mindfulness and performed a meta-analysis to determine how mindfulness explains various types of human motivation. Among these authors' hypotheses was that mindfulness would be positively associated intrinsic motivation and negatively correlated with external motivation. After conducting a systematic review and meta-analysis of 89 studies that met the authors' selection criteria and accounting for bias, the data supported the authors' primary hypothesis that there was a positive association between mindfulness and autonomous motivation.

Moreover, Bergomi et al. (2013) investigated whether mindfulness moderates the association between the occurrence of distressing experiences and mental health. In a community sample of participants, these authors found that mindfulness moderated the association between unavoidable distressing events and psychopathological symptoms/negative affect and the ability to cope with distressing events and increased well-being. According to these authors acceptance of negative events and mindfulness is experiential change, in that the individual can change the function of inner events and the individual’s relationship to those events, which may prove beneficial in addressing avoidance and a capacity to facilitate coping and promote well-being.

Additionally, Tan-Ho et al. (2020) conducted a qualitative study to examine self-determination in the context of caregiving motivations using a sample of primary family caregivers in Singapore. The authors found that six themes emerged that could either positively or negatively impact caregiver well-being. These themes included honoring fidelity, a concept known as filial piety, alleviating suffering, enduring attachment, preserving gratitude, navigating change and reconciling with mortality. The final theme, termed wellbeing determinant, an indicator of self-determination, was found to influence the process by which caregivers appraise their motivations. These authors suggested that fulfilling one’s sense of autonomy is central to the caregiver’s motivations and the ability to find positive meaning in the individual’s motivations and resulting behaviors. Hsieh et al. (2019) sought to identify the mediating effect of mindfulness, self-compassion, compassion from others and caregivers’ dispositional mindfulness as moderators on the relationship between caregiver stress and depression. Care recipients with lung cancer and their caregivers participated in the study. After controlling for care recipients’ illness progression and depressive symptoms and caregivers’ health status, the authors found that mindfulness awareness and self-compassion were significant determinants of PCB.

By contrast, Kose (2019) investigated whether dispositional mindfulness is a protective factor in relation to caregiver burden and whether mindfulness influenced the overall psychological well-being of caregivers. The study was conducted in Turkey and used the Caregiver Well-Being Scale, the Zarit Caregiver Burden Interview, the Basic Personality Traits Inventory, the Mindfulness Attention Awareness Scale and the Beck Depression Inventory. Using both correlation and moderation analyses, the authors found that mindfulness was positively correlated with overall caregiver well-being and negatively correlated with depression. The associations between mindfulness, neuroticism and depression were unclear.

Kabat-Zinn (2015, 2003, 1994, 1990, 1982) conceptualized mindfulness as the individual’s ability to cultivate a position as an impartial witness to one’s own experience. This author proposed mindfulness as an awareness of the dynamic interplay between an individual’s inner and outer experiences and engaging in a conscience and concerted effort to synthesize these experiences into the individual’s consciousness, and then to behave in a manner that is in line with this evolved consciousness. Kabat-Zinn developed a structured eight-week psychoeducational program known as Mindfulness-Based Stress Reduction (MBSR). This author proposed that teaching skills that foster mindfulness may offer individuals the ability to reduce stress related symptomology and improve mood and overall psychological well-being.

To determine whether a mindfulness-based stress reduction program reduced the psychiatric symptoms of caregivers who provide care for frail elders, Epstein-Lubow & Armey (2011) conducted a pilot investigation of mindfulness-based stress reduction

(MBSR) among this segment of the population. Participants were recruited from nursing homes and home care clinical settings who were responsible for the care of a frail elder. Care recipients were seven people diagnosed with dementia and two were frail due to severe medical conditions. Sociodemographic information was collected and analyzed, and an intervention schedule was in place to assess mindfulness at baseline (week 0), after eight weeks of active MBSR participation (week 8) and at a four-week follow-up (week 12). Results of the pilot study were analyzed and were consistent with previous research that depressive symptom improved because of the MBSR intervention but returned after four weeks to baseline level. However, participants reported that awareness and mindfulness continued to increase after the intervention.

Additionally, Whitebird et al. (2012) conducted a randomized controlled trial to investigate the effects of a Mindfulness-based stress reduction (MBSR) intervention as compared to a community caregiver education and support (CCES) intervention. A sample of family caregivers were randomly assigned to either the MBSR or CCES intervention and all participants completed an eight-week program. Assessments were conducted at baseline, postintervention and at six months. Caregivers who participated in the interventions were predominantly non-Hispanic White women (97%) caring for a parent with dementia. The results evidenced that the mindfulness-based stress reduction intervention was more effective in reducing stress, improving overall mental health and decreasing depressive symptoms than the community caregiver education program and support program. However, both interventions improved mental health, reduced anxiety and overall PCB. Implications of this study are that MBSR is shown to be an effective treatment to reduce stress and increase overall mental health among caregivers who provide care to people with dementia.

Social Learning Theory and Locus of Control

Bandura (1997, 1991a, 1991b, 1977, 1973, 1971) theorized that an individual’s psychological functioning is neither dependent on inner nor external forces, but rather is the result of dynamic and continuous interaction between behavior and environmental conditions. Bandura (1971) theorized that behavior is a function of success or failure (rewards or punishments), actualized results, and the psychological conditions during the formation of the psychological forces that drive behavior. Bandura postulated that individuals fully participate in their surroundings, and that behavior, personal factors and the environment are all equal and interlocking determinants of each other. Bandura referred to this concept as reciprocal determinism (Bandura, 1977, 1973). Further, Bandura theorized that behavior was the result of observing, modelling, and imitating the behaviors, attitudes, and the emotional reactions of others through the process of observational learning. Bandura accepted the theory that the environment causes behaviors but theorized that behaviors cause the environment. He referred to this theoretical construct as reciprocal determinism and postulated that behaviors and the environment are integrally and equally related.

Locus of Control

Building on Bandura’s theory, Rotter (1982, 1975, 1954) utilized the empirical law of effect which states that people are innately motivated to seek pleasure and positive stimulation while avoiding unpleasant situations. Rotter (1975) stated that if the outcomes of behaviors were positive or negative, individuals would use the response or behavior that increased the likelihood of a positive outcome, while eschewing the behaviors that resulted in negative outcomes. Locus of control (LOC) according to Rotter (1966) is a personality construct that reflects the individual’s beliefs about who controls their life and the environment. Lee-Kelley (2006) described locus of control as a dimension with two opposing differentiates. Each dimension reflects the individual’s perception or belief that what happens in life is within their control or beyond it (Carrim et al., 2006). People with an internal locus of control believe that what happens to them is more a result of their own personal efforts, personal abilities, and diligence. These individuals believe that hard work results in positive outcomes (Carrim et al., 2006). By contrast, people who possess an external locus of control believe that their actions are dependent on external factors. Rotter (1966) postulated that there are four types of beliefs that comprise external locus of control. These include powerful others, luck or chance, fate and that the world is too complex to be predicted. In many situations, individuals who believe or expect that it is within their capacity to control their destinies will behave differently and achieve positive outcomes than those who believe or expect that their behavioral outcomes are controlled by others or determined by luck (Rotter & Hochreich, 1975).

Band-Winterstein et al. (2019) investigated the nexus between depression and care recipients’ and caregiver’s characteristics, situational factors, and perceived locus of control among Ultra-Orthodox Jewish caregivers. A sample of primary caregivers were interviewed face-to-face using reliable and valid measures. These authors found that there was a significant relationship between depression and caregivers’ characteristics, and a smaller but still significant association between caregivers' personality characteristics [external locus of control (chance)] and self-efficacy. A third model was used to determine the association between situational variables, including social support and taking care of another other than the care recipient. All three models were combined to determine, whether a relationship, if any, existed between depression and the variables. The results of the study suggest that religious beliefs among ultra-orthodox Jews, the population under study, may have a significant impact on mental health outcomes. The authors also found that caregivers with a greater sense of external locus of control experienced greater levels of depression; however, it was determined that self-efficacy is not predictive of depression in this study. The authors suggested that further research is necessary to determine if a relationship exists between care recipients' level of functioning and a caregiver's emotional responses to the level of caregiving, based on the level of the care recipient's physical functioning.

By contrast, Teehan et al., (2016) conducted a systematic review of studies examining resilience among family caregivers of people with dementia from 2006-2016. These authors found that caregiver personality characteristics and level of PCB were positively correlated. The authors suggested that people who reported higher levels of self-efficacy, confidence in their caregiving abilities and perceived locus of control reported lower levels of PCB and increased psychological well-being. This study is also suggested that there are a multitude of factors that influence PCB among family caregivers, however, an analysis of the literature suggested that PCB and the caregivers' perceived control over stressful situations encountered in their caregiving duties are both important.

Summary

The need for informal caregiving has increased significantly in the United States due to the growing elderly population and an increase in the number of people who suffer from dementia and other forms of cognitive decline (Edwards et al., 2020). The COVID-19 pandemic caused a radical change in dementia caregiving (Cohen et al., 2020). Research confirmed that PCB increases and emotional well-being declines among adult informal caregivers following community wide disasters (Russel et al., 2020). Research shows that caregiving impacts the informal caregiver’s emotional, physical and psychological well-being, increases the financial burden experienced by caregivers and reduces the caregiver’s quality of life during a global health emergency (Cipoletta et al., 2021).

While numerous theoretical constructs have shown the negative consequences of caregiving in COVID, none have investigated the influence, if any, of mindfulness and locus of control on the PCB experienced by adult informal caregivers of people with dementia living in the community. In this study, the researcher focused on the influence, if any, of mindfulness and locus of control on the PCB experienced by adult informal caregivers of people with dementia in the aftermath of the COVID-19 global health emergency. As a result of the lack of research, the focus of this study was both timely and essential to effect social change.

From a social change perspective, it is necessary to ensure that adult informal caregivers can provide care to the person with dementia in a manner that enables them to conduct their caregiving duties and ensure the continuity of care during a global health emergency (Cohen et al., 2020) while maintaining their own quality of life and improving their psychological and physiological well-being. The results of this study provided insights into the influence, if any, of mindfulness and locus of control on the PCB experienced by adult informal caregivers of people with dementia living in the community in the aftermath of a global health emergency. The findings from this research may assist researchers and practitioners by providing insights into identifying and developing effective techniques for reducing and mitigating PCB and improving the emotional well-being of adult informal caregivers of people with dementia.

There is a gap in the literature regarding the influence of mindfulness and locus of control on the PCB experienced by adult informal caregivers of people with dementia living in the community in the aftermath of the COVID-19 pandemic. This study examined whether mindfulness and locus of control influence the PCB experienced by adult informal caregivers of people with dementia living in the community.

In this section, I presented an overview of the literature associated with PCB during the COVID-19 pandemic, and the influence of resilience, mindfulness, and locus of control on the PCB experienced by adult informal caregivers of people with dementia. This study investigated the combined and relative effects of mindfulness and locus of control in explaining variance in PCB among adult informal caregivers of people with dementia living in the community in the aftermath of the COVID-19 health emergency.

The section concluded with a description of the study’s potential impact to effect positive social change. The next section presents the research methodology that was used in this study.

Chapter 3: Research Method and Design

People diagnosed with dementia gradually lose the ability to care for themselves and suffer varying degrees of cognitive impairment that worsen over time. Care recipients become dependent on adult informal caregivers to provide the care necessary to engage in ADL and IADL. Adult informal caregivers experience varying degrees of burden commensurate with the level of care required by the care recipient. Further, the COVID-19 pandemic exacerbated the burden perceived by adult informal caregivers and exacted an emotional, financial, and physiological toll on adult informal caregivers as well as care recipients. A better understanding of PCB was required to ensure the quality of life of the adult informal caregivers and ensure that caregivers maintain optimum physical and emotional health during a global health emergency and its aftermath. The purpose of this quantitative correlational study was to examine the influence of mindfulness and locus of control, if any, on the PCB experienced by adult informal caregivers of people with dementia while controlling for demographic characteristics including gender, marital status, and education. This chapter presents the research design and the rationale of the study. It also includes the methodology and threats to validity.

Research Design and Rationale

The independent variables in this study were mindfulness, which was measured using the MAAS (Brown & Ryan, 2003a), and locus of control, which was measured using the LOCS (Rotter, 1966). The dependent variable was PCB, which was measured using the CBI (Novak & Guest, 1989). I employed a quantitative correlational design that was administered to adult informal caregivers of people with dementia to determine the extent to which a relationship, if any, exists between research variables. Quantitative data were gathered from participants using measures designed to capture whether locus of control and mindfulness influenced PCB among adult informal caregivers of people with dementia living at home. By using quantitative correlational methodology, I was able to answer the research question and the associated null and alternative hypotheses. A correlational design was appropriate to examine the variables to determine whether there is a statistical link.

Hierarchical multiple linear regression was selected because it was the most appropriate data analysis method to assess the relationship, if any, between mindfulness and locus of control and PCB among adult informal caregivers of people with dementia. Although numerous studies investigated the relationship between mindfulness and caregiver burden, no studies had examined the influence, if any, of mindfulness and locus of control on the PCB experienced by adult informal caregivers of people with dementia living in the community. The knowledge gained from this study may inform interventions that could improve the physical and mental health of those dealing with high levels of burden.

Methodology

Population

The target population for this study was adult informal caregivers who provided care to people with dementia at home. The sample size for this study was 104 adult informal caregivers of people with dementia.

Sampling and Sampling Procedures

A nonprobability sampling approach was used. Because individuals were easy to access and the technique is affordable, a convenience sampling strategy was ideal for this study. A specific sample size could be chosen that was representative of the population of adult informal caregivers. According to Creswell (2009), this sampling strategy enables researchers to enroll people to participate in a study by picking a certain number of people from a group. Although convenience sampling is a less time-consuming method, the researcher must be cognizant of sampling bias because the sample may not be representative of the overall population (Creswell, 2009). Participants were providing comparable levels of care. In addition to the adult informal caregiver being a relative of the care recipient, the participants confirmed that the person with dementia lived in the same residence. Maintaining the adult informal caregiver criteria was critical to address the study's hypothesis and reduce adult informal caregiver variability. Excluded from the study were people who did not provide full-time care or those who provided care for individuals in a nursing facility.

An a priori analysis using the G*Power tool was conducted to determine the sample size to ensure accuracy and validity (see Faul et al., 2009). The alpha level was set at .05 with a power of .95 and Cohen's *f*2 =.10 based on an *f* test with five predictors. The G*Power tool calculated that the minimum sample size required was 150. Data collection commenced and continued until February 10, 2023, when all avenues of data collection were exhausted and a sample of 104 completed surveys was obtained.

Procedures for Recruitment, Participation, and Data Collection

Participants were adult informal caregivers of people with dementia living at home. Participants were recruited from social media platforms on Facebook and the National Alzheimer's Association TrialMatch platform via an online invitation. The ad approved by the institutional review board (IRB) provided details on the purpose of the study, the potential risks and benefits of the research, the rights of the participants, the potential risks of participating, and the requirement of approximately 45 minutes to complete the surveys. Participants were advised that they could terminate their participation in the study at any time for any reason, and that any responses to the surveys would be collected without any identifying information. Approval was obtained from the Walden University IRB (09-14-220113631). An IRB approved online flyer describing the study and inviting people to participate was posted on social media platforms.

Inclusion criteria included adult informal caregivers over 18 years of age who provide care to people with dementia living at home. Inclusion criteria were explained to potential participants in the screening question. Once interest in the study was expressed, individuals were directed to the screening question at the commencement of the survey and the informed consent document. Participants were notified that participation was optional and that they could withdraw consent at any point during the survey. Prior to starting the surveys, participants were required to read and acknowledge their understanding of the estimated time to complete the survey and acknowledge that they had read and understood the informed consent document. While participating in the study, adult informal caregivers self-reported that the care recipient received a diagnosis of dementia. Including a dementia diagnosis as a criterion reduced care recipient variability.

Participants were ensured that data collected from the study would be anonymous, and that no identifying information would be requested or collected. Participants provided demographic information including their gender, marital status, education, employment status, and years of care recipient’s illness. To secure sensitive information, I kept data in a secured file on my computer that required a password known only to me.

Data Collection Procedures

The survey was conducted via an online link using Survey Monkey, a secure platform that allowed for the dissemination of the survey and the encrypted collection of data and data transfer. Informed consent was obtained when the study participant entered SurveyMonkey and responded in the affirmative to the informed consent document and the screening question. Data were collected using a survey format that included sociodemographic questions and three measures: the CBI (Novak & Guest, 1989), the MAAS (Brown & Ryan, 2003), and the LOCS (Rotter, 1966). The survey link was provided by the online ad, and each participant acknowledged the informed consent document prior to entering the main body of the survey. Participants completed the survey instrument online and in the privacy of their homes. All completed survey instruments were based on the caregiver’s self-report about their caregiving experiences. To reduce the amount of time it took to complete the survey, I grouped the instruments under one link so that participants did not have to click on numerous links. Completed survey instruments were collected by me directly from the SurveyMonkey website. The survey was open until February 10, 2023, when I determined that all avenues of data collection had been exhausted and 104 participants had completed the survey. Using the statistical software program IBM SPSS, I analyzed the data, which were protected by a password entry. After the participant had completed and submitted the survey, there was no follow-up. Participants were not compensated for their time.

Research Question and Hypotheses

RQ1: What are the combined ($R2$) and relative ($sr2$) effects of locus of control and mindfulness in explaining variance in PCB, controlling for relevant sociodemographic characteristics?

H_o1: Locus of control and mindfulness do not explain variance in PCB, controlling for relevant sociodemographic characteristics.

H_a1: Locus of control and mindfulness explain variance in PCB, controlling for relevant sociodemographic characteristics.

Instrumentation

Sociodemographic Questionnaire

Demographic questions included the adult informal caregiver’s gender, marital status, education, occupation, and the years of the care recipient’s illness.

MAAS

MAAS is a single factor measure for mindfulness containing 15 items. The 15-item scale was designed to assess core characteristics of mindfulness, in particular the state of mind in which attention, informed by a sensitive awareness of what is occurring in the present, simply observes what is taking place (Brown & Ryan, 2003). The MAAS assesses individual differences in the frequency of mindful states over time. The scale is a 15-item (1-6 Likert scale) questionnaire to assess dispositional (trait) mindfulness. The measurements from the questionnaire tap into consciousness related to self-regulation and various areas of well-being. Higher scores indicate more mindfulness, and a minimum score of 15 and a maximum score of 90 pints can be reached (Carlson & Brown, 2005). The scale shows good reliability with Cronbach's alpha of 0.89 (Black et al., 2012).

LOCS

The LOCS (Rotter, 1966) is a 29-item questionnaire that measures an individual's level of external-internal control, or the degree to which an individual interprets events as being the result of their own actions or external forces. Locus of control is a psychological construct that refers to the degree to which an individual perceives that a reward follows from or is contingent on their own behaviors or attributes or the degree to which they feel that rewards are controlled by external forces or luck, and which occur independent from their own actions. People with an internal locus of control believe that they exercise control over the events in their lives and that outcomes are determined because of their effort or abilities. People with an external locus of control believe that their behaviors or decision making has little or no impact on outcomes and that external forces beyond their control, such as luck, chance, fate, or powerful others, control the outcomes of events in their lives.

The LOCS questionnaire is a forced choice instrument where a respondent must select a specific answer for each item. The respondent must select the statement they most agree with from an 'a' or 'b' option and contains two sentences as 'a' or 'b' on important social events (Hosseini et al., 2016). The 29-item LOCS questionnaire contains filler items to make the purpose of the survey ambiguous. Scores range from 0 to 13, with lower scores indicating an internal locus of control and higher scores indicating external control. Twenty-three items evaluate locus of control, and six items provide ambiguity and to mask the given scale. Each ‘a’ choice equals one score point, and each ‘b’ choice is given a zero-score point. The LOCS may be administered as a self-report instrument or completed by the interviewer or researcher. Rotter (1966) reported that this scale correlates well with other methods used to assess locus of control such as a set of questions and Likert scale.

Judge and Bono (2001) conducted a meta-analysis of 216 studies and found that internal locus of control was positively correlated with both job satisfaction and job performance. The existing body of research on locus of control indicates that it is positively correlated with positive cognitive functioning in numerous areas. However, no studies to date have investigated whether locus of control is positively correlated with reducing the higher burden experienced by adult informal caregivers of people with dementia in general, or in the context of the additional stressors associated with the COVID-19 pandemic.

CBI

Novak and Guest (1989) developed the Multidimensional Caregiver Burden Inventory (CBI) that measures five dimensions of burden – time, dependence, developmental, physical, social, and emotional burden. It is a 24-item multidimensional measure of caregivers’ responses to the demands of providing care. (Reid, et al., 2005).

Items in the CBI provide descriptions of various caregiving situations and respondents rate the extent to which these items reflect their own situation on a five-point Likert scale ranging from “never” to “nearly always.” All but the physical burden subscale consists of five items (Caserta, et al., 1996). The physical burden score, which is based on four items, is weighted by a factor of 1.25 to allow its range to be equivalent to the other subscales (Novak & Guest, 1989).

The present study utilized all the subscales in the CBI. These subscales included time dependency, developmental, physical, social, and emotional burden. Developmental burden measures the extent to which caregivers’ feel trapped within their roles (Novak & Guest, 1989). Physical burden measures the impact of caregiving on the caregiver’s physical health. Social burden measures the caregiver’s feelings of ungratefulness as well as balancing their personal life with their role as a caregiver (Reid et al., 2005). Emotional burden gauges the extent to which caregivers experience negative feelings toward the care recipient (Novak & Guest, 1989).

The present study utilized all the subscales in the Caregiver Burden Inventory. These subscales included time dependency, developmental, physical, social, and emotional burden. Developmental burden measured the extent to which caregivers’ feel trapped within their roles (Novak & Guest, 1989). Physical burden measures the impact of caregiving on the caregiver’s physical health. Social burden measures the caregiver’s feelings of ungratefulness as well as balancing their personal life with their role as a caregiver (Reid et al., 2005).

Emotional burden gauges the extent to which caregivers experience negative feelings toward the care recipient (Novak & Guest, 1989). Each subscale ranges from 0 (low) to 20 (high). High scores reflect more pronounced burden (Reid et al., 2005). The CBI has revealed reasonable reliability with Cronbach’s alpha for the subscales ranging from 0.73 to 0.86 (Novak & Guest, 1989).

The intent of the study was to examine specific correlations between the following variables: (a) caregiver burden, as measured by the CBI; (b) locus of control as measured by the LOCS; (c) trait mindfulness as measured by the MAAS; the relationship between caregiver burden and locus of control; the relationship between caregiver burden and mindfulness; and the relationship between caregiver burden and LOC and mindfulness. Using these measures, the following correlations were analyzed: (a) CBI and LOC, (b) CBI and MAAS, and (c) CBI, LOC, MAAS. I hypothesized that all the correlations will be positive and statistically significant.

I obtained permission from the creators of each instrument, or in the alternative, provided documentation that evidenced that an instrument is open for public use and no permission was required. These documents are included in Appendix G.

Data Analysis Plan

The predictive analytics program IBM SPSS Statistics (Version 28) was used to evaluate the data. Hierarchical multiple linear regression was used to estimate the relationship between the two independent variables and one dependent variable (Ming Liew et al., 2019). Hierarchical multiple linear regression was utilized to determine the strength of the relationship between the two independent variables (LOCS and MAAS) and the dependent variable (Caregiver Burden Inventory). Significance was determined at $p < .05$. The assumption of multiple linear regression is the homogeneity of variance (homoscedasticity) or the size of the error in the prediction does not change significantly, and the data follows a normal distribution and linearity. Several studies have utilized multiple linear regression to determine the relationship, if any, between caregiver burden (CB) and caregiver characteristics. Marsack-Topolewski & Church (2019) employed multiple linear regression to determine the impact of caregiver burden on the quality of life (QoL) for parents of adult children with autism spectrum disorder. These authors found that two variables, developmental burden and the impact of caregiving on finances were statistically significant predictors of QoL.

Ming Liew et al. (2019) employed multiple regression analysis to determine the relationship, if any, between caregiver burden and pre-death grief (PDG) in caregivers of people with dementia. These authors found, after an analysis of the data, that risk factors for PDG and caregiver burden were different and that there is a distinction between PDG and caregiver burden. Tsai et al. (2021) employed multiple linear regression to determine the correlations between caregiver burden and characteristics of caregivers and care recipients. These authors concluded that caregiver burden is highest among the older caregivers of older demented patients.

By reviewing the responses and comparing the information entered in the SPSS program to the information collected from the original surveys, the findings were evaluated for correctness and validity to verify that all information was recorded properly and thoroughly. A descriptive data analysis method was employed to explain the sample means, standard deviations, probability values, and medians to identify skewness, search for outliers, and detect missing data. Hierarchical multiple linear regression analyses was used to determine if there was a relationship, between mindfulness and locus of control on the PCB experienced by adult informal caregivers. This study was designed to examine the correlations between mindfulness, locus of control and PCB.

Descriptive statistics was used to analyze the sociodemographic data (See Appendix D). Brown and Ryan (2003) operationalized trait mindfulness using the 15-item unidimensional MAAS using a series of psychometric development studies. In the Brown & Ryan study, the MAAS had good internal consistency ($a \geq .82$) and was positively correlated with number of years of meditation practice ($r = .36$, $p < .05$). The MAAS has maintained a significant relationship with well-being even after adjusting for other psychosocial measures (Brown & Ryan, 2003) indicating its incremental validity as a mental health construct. All items are rated on a 6-point Likert scale (6=*almost never*; 1=*almost always*) designed to measure the extent to which individuals pay attention during several tasks, by contrast, to behaving “automatically” without paying attention to the task at hand, and the summated score can be computed for the MAAS total score, where a higher score indicates a higher level of mindfulness (See Appendix D).Rotter (1966) proposed that locus of control is a specific criterion that influences the extent to which a person is affected by a stressful event and the degree of the control that the individual has over the stressor (Southwick, 2012).

Rotter (1966) postulated that internal versus external locus of control refers to the degree to which individuals expect that an outcome of their behavior is contingent on their own behavior or personal characteristic versus the degree to which people expect that the outcome is a function of chance, luck or fate, and that outcomes are under the control of powerful others or fundamentally unpredictable. Rotter’s original conception, locus of control, was a unitary construct along the internality-externality dimension. However, other researchers have since proposed independent dimensions of internality, chance, and powerful others.

Numerous studies have investigated the stability and change of locus of control among children and adults over time (Nowicki et al., 2018); the lack of perceived personal control as an explanatory factor of burnout in professional caregivers of older adults (Nieto et al., 2022); and changes in locus of control over time among people with dementia (Halse et al., 2021).

Rotter’s Locus of Control Scale (LOCS; 1966) is comprised of 29 statement pairs where the individual chooses the one that best reflects their beliefs (forced choice) and measures an individual’s level of internal versus external control of reinforcement. A high score denotes an external locus of control, while a low score evidences an internal locus of control.

Threats to Validity

The extent to which a study accurately measures what it intends to measure and explores whether the researcher’s conclusions of the obtained data is correct and accurate is the measure of validity in research. Threats to internal and external validity may arise in research.

External Validity

External validity relates to the ability of data results to be used and applied in a variety of locations, groups, and circumstances (Druckman et al., 2011). The use of a convenience sample poses an external validity risk in the proposed study since the sample would not be representative of the total population and might result in a greater degree of sampling error. The risk of external validity was mitigated by informing all survey participants that their replies would be anonymized and kept private.

Internal Validity

Internal validity examines if the predictors influence the dependent variable's behavior. Mortality is one aspect that might jeopardize the planned study's internal validity. Adult informal caregivers may encounter obstacles that prevent them from completing the surveys, including time constraints, physical health problems and additional time required to care for the changes in the needs of the person with dementia.

Construct Validity

There are no anticipated threats to construct validity when measuring the proposed variables. The instruments proposed for use in the study have been used in previous research and have been found to be reliable measures in previous research.

Ethical Concerns

It is incumbent on researchers to anticipate the ethical issues that may arise during studies (Hesse-Biber & Leavy, 2011). According to Punch (2005) research involves collecting data from people about people. Researchers need to protect their research participants; develop a trust with them; maintain the integrity of their research; guard against improprieties and misconduct; and cope with new and challenging problems (Isreal & Hay, 2006). Ethical issues may arise in all aspects of research from the identification of the problem under study to data collection, analysis, and storage of the data. Further, both the researcher and the participants should benefit from the research (Creswell & Creswell, 2018). During this study, certain ethical issues may have arisen, in addition to those mentioned above, including maintaining the anonymity of participants and ensuring that the research will not use language or words that are biased against people because of gender, sexual orientation, race, ethnic group, disability, socioeconomic status or age, and include an acknowledgement of the participants in a study by referring to participants as participants.

Approval from the Institutional Review Board (IRB) at Walden University was obtained to conduct the study. The concept of justice requires the fair selection of research participants, while keeping a focus on the nature of the research and the subject matter under study. In this study, the participants were homogenous to those who could benefit from the research and its conclusions. The principle of justice requires that certain groups not be excluded from the research however, as there are certain criteria for inclusion for this study, only Adult informal caregivers of people with dementia were included as this is the group of particular interest to this research. Justice further requires that all persons have access to and benefit from the contributions of the research (APA Code of Ethics, 2017). Obtaining informed consent from each participant prior to disseminating the survey materials is an ethical issue that may emerge during the recruitment process (Hennink et al., 2020). An ethical issue that may have arisen during the study was thoroughly communicating with the participants from the commencement of the study through the conclusion (Hennink et al., 2020) and confirming their willingness or unwillingness to participate in the study process, thereby insuring the welfare and rights of the research participants and other affected persons. Another ethical concern that may have arisen during the study was that people in the participant's community may become aware of the research topic, or information disclosed by the participants to the researcher resulting in damage to the participants' reputations (Hennink et al., 2020). In the proposed study, measures were implemented to minimize any adverse psychological harm that may have occurred because of the participant's emotional experiences. To minimize any ethical concerns, the participants were required to acknowledge the consent form prior to entering the survey. Other ethical considerations that were contemplated were that the sample may not have been representative of all adult informal caregivers of people with dementia as the recruitment process was conducted through online platforms through Facebook dedicated to adult informal caregivers of people with dementia and the National Alzheimer's Association TrialMatch platform. The selection of participants was predetermined through stipulations (i.e., limited to adult informal caregivers of people with dementia living at home). Research participants were not excluded based on race, ethnic group, gender, sexual orientation, or socioeconomic status. Additionally, monetary rewards, gifts or other compensation were not offered because these may have been construed as ethical improprieties (Cozby & Bates, 2012). Participants were not coerced to participate, advised that participation was voluntary, and that the participants were free to withdraw from the study at any time until the voluntary submission of the survey or by the assumption that rewards or monetary gifts will be provided to encourage participation. These procedures ensured that the data collected was accurate and not coerced because of the promise of rewards.

Informed consent was obtained from each participant prior entry into the online survey. A copy of the informed consent document is attached as Appendix “B “. Only after the informed consent form was electronically acknowledged was the participant allowed to enter the survey. The completion of the survey was optional, and participants were reminded prior to submission of each section of the survey that participation was voluntary, and that the participant could withdraw consent at any time prior to the completion of the survey or any part thereof. All participants were informed of the process to maintain confidentiality of the participants and how the data was protected throughout the research process.

Access to the data was available only to the researcher to maintain confidentiality. Data obtained was kept confidential and was accessible only through a secured password. If during the survey process any participant experienced emotional or psychological distress, the participant was offered the opportunity to exit the survey. The participants were expected to face minimal risks because the research ad explained the study’s goal and nature. All participants were given the researcher’s contact information in case they had any concerns or needed assistance before or during the study. The data collected was properly secured and will be stored for a period of five years before it is destroyed in accordance with Walden University’s policy. The ethical consideration for the researcher is to value the participants, their beliefs and to protect their confidentiality.

Summary

The purpose of this quantitative correlational survey design was to examine the influence, if any, of mindfulness and locus of control on the PCB experienced by adult informal caregivers of people with dementia living at home, post pandemic. The research design, sample population, research questions and instruments are detailed in this chapter. The chapter detailed the data collection process, potential threats to validity, ethical considerations and the proposed analysis of the data collected. To input and evaluate the data, the researcher used the IBM SPSS version 28 software application. Hierarchical multiple linear regression analyses were used in this quantitative correlational design with the following predictors: mindfulness and locus of control.

The findings of the current study are discussed in detail in Chapter 4. Chapter 4 features quantitative and statistical analysis that present the significant and non-significant findings. Descriptive statistics are displayed in the relevant table, and the effect sizes of the various predictor variables are also displayed in tables. Prior research has evidenced that adult informal caregivers of people with dementia experience varying degrees of psychological, emotional, and physical burden during the trajectory of their caregiving responsibilities (Etters et al., 2008; Bruvik et al., 2013; Ulstein et al., 2007). It is well-settled that adult informal caregivers to people with dementia experience higher levels of burden than caregivers of people with other chronic medical conditions (Papastavrou et al., 2012). It is important to note that no studies have investigated the influence, if any, of mindfulness and locus of control on the PCB experienced by adult informal caregivers to people with dementia. Given the after effects of the COVID-19 pandemic on caregiving, and the increasing needs for adult informal caregivers of people with dementia, the increasing need for adult informal caregivers of people with dementia, and the exacerbation of PCB on adult informal caregivers to people with dementia, more should be done to address whether mindfulness and locus of control mediate the PCB experienced by adult informal caregivers and whether these variables increase the well-being of both adult informal caregivers and people with dementia. The literature provides additional insights into how mindfulness and locus of control may influence the PCB experienced by adult informal caregivers to people with dementia during a global pandemic and after a pandemic becomes endemic. An analytical focus on the influence of mindfulness and locus of control on the PCB experienced by adult informal caregivers may provide insights into the initial development of interventions to address the experience of PCB among adult informal caregivers to people with dementia during global health emergencies or its aftermath.

Chapter 4: Results

The primary objective of this quantitative study was to answer the research question: What are the combined (R2) and relative (sr2) effects of locus of control and mindfulness in explaining variance in PCB, controlling for relevant sociodemographic characteristics? This chapter provides the results of the statistical analyses using SPSS software Version 28. Three hierarchical linear regression models were used to answer RQ1. Results were considered statistically significant at $p < 0.05$.

At the time of this, no previous studies had been conducted to examine the combined and relative effects of locus of control and mindfulness on the PCB experienced by adult informal caregivers of people with dementia living in the community. An examination of these two measures on PCB was necessary to provide adult informal caregivers and the scholarly community with insights into how mindfulness and locus of control may influence the PCB as experienced by this segment of the caregiving population. This chapter is divided into four subsections. The first subsection describes the data collection procedures and treatment of variables in the data set. The second subsection describes the adult informal caregivers' personal demographic characteristics including the care recipient's diagnosis and the number of years of the care recipient's illness. The third subsection presents means and bivariate correlations of the key outcome measures. The fourth subsection presents results of the regression analyses.

Data Collection and Treatment of Variables

Data were collected using Survey Monkey, a secure platform that allowed for the dissemination of the survey and the encrypted collection of data and data transfer. Prior to conducting data analyses, the data file was examined, and new variables created using SPSS to allow for interpretable hierarchical multiple regression analyses. Total score and dummy coded variables for continuous and categorical variables were computed as appropriate for regression analyses. For gender, male was coded as 1, female as 2. For marital status, married/domestic partnership was coded as 1, all else was coded as 2.

Participant Characteristics

The participants in this study were adult informal caregivers of people with dementia living in the community. A final *N* of 104 was obtained. Participants were mostly female (*n* = 74, 71.2%), married (*n* = 54, 51.9%), working full-time (*n* = 32, 30.8%), and had at least a college education (*n* = 78, 75.0%). Full demographic characteristics are reported in Table 1.

Table 1

Demographic Frequencies and Percentages for Responses

Demographic	Category	Number	Percentage
Gender	Male	27	26.0%
	Female	74	71.2%
Marital status	Married/living with partner	58	55.7%
	Widowed	8	7.7%
	Divorced/separated	20	19.2%
	Single, never married	17	16.3%
	Prefer not to answer	1	1%
Occupation	Working full-time	32	30.8%
	Working part-time	14	13.5%
	Remote full-time	21	20.2%
	Remote part-time	4	3.8%
	Not working	33	1.7%
Education	Elementary	1	1.0%
	High school	25	24.0%
	College (undergraduate)	47	45.2%
	Graduate degree	25	24.0%
	Postgraduate degree	6	5.8%
Care recipient diagnosis	Dementia (not specified)	42	41.9%
	Alzheimer’s	25	4.0%
	Senile dementia	6	5.8%
	Frontotemporal dementia	5	4.8%
	Lewy body dementia	7	6.7%
	Vascular dementia	12	1.5%
	Unknown	7	6.7%
Years of care recipient’s illness	Less than 3 years	35	33.7%
	3–5 years	40	38.5%
	5–10 years	17	16.3%
	10 years or more	10	9.6%
	Don’t know	2	1.9%

Means and Correlations Among Key Variables

The mean, standard deviation, and range for LOC was 8.68 (*SD* = 3.19, range 0–12). The mean, standard deviation, and range for MAAS was 56.48 (SD = 15.04, range 29.00–89.00). The mean, standard deviation, and range for CBI was 56.02 (*SD* = 12.33, range 18.00–89.00). The correlations among the three measures were as follows: LOC-MAAS *r* (94) = 0.06, *p* = .598; LOC-CBI *r* (94) = -.15, *p* = .146; MAAS-CBI *r* (94) -.33, *p* = .001.

Hierarchical Multiple Linear Regression

Three hierarchical linear regressions were conducted to analyze the data to determine whether there was support for the alternative hypothesis. Key assumptions for conducting multiple linear regression were evaluated, and no issues were detected. In all three analyses, PCB was the dependent variable, as measured by CBI, and the independent variables were the locus of control, as measured by LOCS, and mindfulness, as measured by MAAS. An analysis was conducted to determine the combined (*R*2) and relative (*sr*2) effects of LOCS and MAAS on the CBI while controlling for sociodemographic characteristics including gender, marital status, employment, education, and years of care recipient's illness.

The first analysis examined the influence of locus of control on caregiver burden while controlling for sociodemographic characteristics. In Block 1, all covariates described were entered in the model. In Block 2, the total score for the locus of control measure was entered. For Block 1, *R* = .286, *R*-squared = .082, *F* (5, 85) = 1.52, *p* = .193. For Block 2, *R* = .301, *R*-squared = .091, *F* (1, 84) = .799, *p* = .374. As depicted in Table

2, education was a marginally significant predictor of CBI in Block 2 (β = [standardized beta] = -.203, t = -1.872, p =.065, sr^2 =.045). In Block 2, when locus of control was added, locus of control was not a significant predictor of CBI total scores (β = -.096, t = -.894, p =.374, sr^2 = .010). No other predictors were statistically significant (see Table 2).

Table 2

Multiple Linear Regression Analysis Examining Locus of Control Scores as a Predictor of Caregiver Burden Inventory Scores

Block	Predictor	*β*	*t*	*p*	*sr2*
Block 1	Gender (female)	.094	.884	.379	.010
	Marital status (married)	-.145	-1.327	.188	.023
	Occupation (working full-time)	-.105	.947	.346	.011
	Education (college and above)	-.220	-2.062	.042	.047
	Years of CR illness	-.036	-.342	.733	.001
Block 2	Gender (female)	.082	.764	.447	.009
	Marital status (married)	-.145	-1.251	.215	.021
	Occupation (working full-time)	-.103	-.921	.360	.010
	Education (college and above)	-.203	-1.872	.065	.045
	Locus of control	-.096	-.894	.374	.010

The second analysis examined the influence of mindfulness on caregiver burden while controlling for sociodemographic characteristics. In Block 1, all covariates were entered into the model. In Block 2, the total score for MAAS was entered. For Block 1, R =.292, R-squared = .085, F (5, 86) = 1.61, p = .167. For Block 2, R = .405, R-squared = .164, F (1, 85) = 7.95, p = .006. As depicted in Table 3, mindfulness was a significant predictor of CBI in Block 1 (β = -.291, t = -2.819, p =.006, sr^2 = .078).

Table 2

Multiple Linear Regression Analysis Examining Mindfulness Awareness Attention Scores as a Predictor of Caregiver Burden Inventory Scores

Block	Predictor	*β*	*t*	*p*	*sr2*
Block 1	Gender (female)	.124	1.178	.242	.009
	Marital status (married)	-.814	.692	-.125	.021
	Occupation (working full-time)	-.547	.797	-.073	.010
	Education (college and above)	-2.344	1.425	-.167	.104
	Years of CR illness	.816	1.171	-.071	.045
Block 2	Gender (female)	.083	.816	.417	.009
	Marital status (married)	-.125	-1.177	.242	.021
	Occupation (working full-time)	-.073	-.687	.494	.010
	Education (college and above)	-.167	-1.644	.104	.045
	Years of CR illness	-.071	-.697	.488	.001
MAAS total		-.291	-2.819	.006	.078

The third analysis examined the influence of mindfulness and LOC on caregiver burden while controlling for sociodemographic characteristics. In Block 1, all covariates were entered into the model. In Block 2, the total score for MAAS and locus of control were entered. For Block 1, *R* = .285, *R*-squared =.081, *F* (5, 82) = 1.44, *p* = .217. For Block 2, *R* = .409, *R*-squared =.167, *F* (2, 80) = 4.15, *p* = .019. As depicted in Table 4, mindfulness was a significant predictor of CBI; however, locus of control was not a significant predictor of CBI in Block 2 (*β* = -.292, *t* = -2.772, *p* =.007, sr^2 = .080).

Table 3

Hierarchical Multiple Linear Regression Analysis Examining the Combined (sr2) Effects of Locus of Control Scores and Mindfulness Awareness Attention Scores as Predictors of Caregiver Burden Inventory Scores

Block	Predictor	*β*	*t*	*p*	*sr2*
Block 1	Gender (female)	.118	1.090	.279	.009
	Marital status (married)	-.170	-1.534	-.129	.021
	Occupation (working full-time)	-.099	-.879	.382	.010
	Education (college and above)	-.193	-1.784	.078	.045
	Years of CR illness	-.038	-.353	.725	.001
Block 2	Gender (female)	.068	.639	.525	.004
	Marital status (married)	-.118	-1.087	.280	.012
	Occupation (working full-time)	-.070	-.643	.382	.010
	Education (college and above)	-.153	-1.441	.153	.021
	Years of CR illness	-.065	-.619	.538	.003
MAAS total		-.292	-2.772	.007	.080
LOC total		-.076	-.719	.474	.005

Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this study was to investigate the combined and relative effects of locus of control and mindfulness on PCB, while controlling for sociodemographic characteristics. The findings of this study may assist scholars, researchers, practitioners, and health care professionals in developing more effective interventions to mitigate PCB and incorporate comprehensive mindfulness techniques to enhance the quality of life of informal caregivers and their care recipients. The sociodemographic variables included gender, marital status, occupation, education, and years of care recipient’s illness. The nature of the study was quantitative using primary data collected via an online survey using SurveyMonkey. The three measurements employed were the CBI (Novak & Guest, 1989), LCS (Rotter, 1966), and MAAS (Brown & Ryan, 2003).

The objective of the research was to examine relationships between locus of control and PCB, mindfulness and PCB, and locus of control and mindfulness and PCB, while controlling for sociodemographic characteristics. At the time of the study, no studies had included measures of locus of control and mindfulness to determine the effects, if any, on the PCB experienced by adult informal caregivers of people with dementia. The results of the multiple linear regressions showed no statistically significant relationship between locus of control and PCB. There was a statistically significant relationship between mindfulness and PCB.

Interpretation of the Findings

Findings Related to Social Learning Theory

One of the theoretical frameworks for this study was social learning theory (Bandura, 1971). Building on Bandura's (1971) social learning theory, Rotter (1966, 1975) theorized that people are innately motivated to seek pleasure and positive stimulation while avoiding unpleasant situations. According to Rotter, locus of control is a personality construct that reflects an individual's beliefs about who controls their life and environment. The results of the current study showed that locus of control had no statistically significant effect on PCB.

Although a plethora of studies investigated the influence of locus of control on caregiver stress in numerous environmental, social, cultural, and religious contexts, there had been few studies that investigated the influence of locus of control on caregiver burden as experienced by adult informal caregivers of people with dementia. One of the few recent studies that examined locus of control and its influence on the negative emotional and physical health outcomes experienced by adult informal caregivers of people with dementia was conducted by Band-Winterstein et al. (2019) who investigated locus of control in the context of negative psychological outcomes and stress experienced by ultra-Orthodox Jewish informal caregivers. The results showed that three factors were significant predictors of higher depressive symptomology and increased burden and stress: higher external locus of control (fate, luck, or chance), being the spouse of the care recipient, and lower levels of social support. Further, Band-Winterstein et al. noted that the small sample size (112) was an impediment to a complete examination of the intensity of depression and burden in the context of the two major theoretical frameworks on which the study relied. Band-Winterstein et al. recommended that public resources should be allocated to target spousal caregivers with lower levels of social support and external loci of control to alleviate psychological symptoms and caregiver burden.

In a related study, Golinska and Obuchowska (2022) evaluated factors that contribute to the quality of life of caregivers of people with dementia. The results showed that locus of control was not found to significantly account for the severity of the caregiver’s burden. The results showed that lower quality of life was associated with more severe depressive symptoms and an increase in the subjective burden experienced by caregivers.

Contador et al. (2015) found that people who possess an external locus of control orientation believe that anything is possible. Contador et al. examined the relationship between optimism and external locus of control in the context of decision making. Contador et al. sought to determine the nexus between optimism and locus of control among caregivers who decided to keep their care recipients in the home compared to those who enrolled them in adult day care. Findings indicated that low scores in grounded optimism were significantly related to day care center use. Further, Contador et al. found that higher scores in external locus of control and depression were significantly related with day care use. Contador et al. concluded that high scores in external locus of control were predictive of specialized day care use; participants with high scores in grounded optimism were less likely to use day care services. The results indicated that caregivers who used day care centers reported higher levels of caregiver burden and depression and scored lower in grounded optimism than caregivers in the in-home group after controlling for covariates such as burden. Contador et al. concluded that optimistic caregivers are less likely to experience negative emotions, which in turn prolongs care in the home.

Caregiver burden as experienced by informal caregivers of people with dementia often manifests as a negative counterresponse emanating from somatic, psychological, emotional, social, and financial stressors. When burden is perceived as overwhelming, a caregiver's counterresponse may include overwhelming feelings of anxiety and stress that may lead to an increase in symptoms of depression and anxiety. The results of the current study showed no statistically significant relationship between locus of control and PCB.

Findings Related to Social Determination Theory

Mindfulness is a theoretical construct based on social determination theory (Deci & Ryan, 1985). Mindfulness is considered an essential element for the integrated regulation of behavior and autonomous self-regulation. Mindfulness is a synthesis of the internal and external awareness of the present moment that allows individuals to become aware of what is occurring within themselves and the environment around them to make purposeful decisions (Brown & Ryan, 2003). In the current study, mindfulness was statistically significant in predicting PCB. Multiple linear regression was used to assess whether mindfulness predicted PCB. The overall regression was statistically significant.

Weisman de Mamani et al. (2018) investigated the interplay between mindfulness, caregiver burden, and mental health in family members of individuals with dementia. Weisman de Mamani et al. examined the association between caregiver objective burden and subjective burden, mindfulness, and quality of life. The results indicated that caregivers who experience greater objective and subjective burden also experience more severe mental health issues, including anxiety and depression. Further, the results showed a statistically significant relationship between increased mindfulness and lower caregiver burden. Findings from this study suggested that increased mindfulness is positively associated with greater mental health outcomes and decreases in caregiver burden but provided no support that mindfulness is connected to reductions in the severity of mental health issues through a reduction in caregiver burden.

Tan et al. (2023) investigated the relationship between mindfulness, caregiver burden, depression, and anxiety among caregivers of people with dementia. The results showed that psychological flexibility and mindfulness were significantly related to lower levels of caregiver burden and lower levels of depressive and anxiety symptoms. However, mindfulness alone did not modulate caregiver burden. Further, the results showed that psychological inflexibility was a significant predictor of increased burden, as well as depressive and anxiety symptoms.

Other studies that considered mindfulness and caregiver burden investigated the impact of mindfulness-based stress reduction and mindfulness-based cognitive therapy on caregivers of people with dementia. Cheung et al. (2020) investigated the efficacy of a modified MBSR and mindfulness-based cognitive therapy aimed at reducing stress, depressive symptoms, and subjective burden among caregivers of people with dementia. The results showed that for both groups, there was a positive relationship between the interventions and reductions in stress, subjective burden, and depressive symptoms. The analysis of the data also indicated that the modified mindfulness-based cognitive therapy had a larger effect on stress reduction compared to the modified MBSR. Further, a postintervention analysis and follow-up with participants, which occurred after 3 months, showed that both protocols were effective in reducing stress, subjective burden, and depressive symptoms.

Other researchers focused on the role that Acceptance and Commitment Therapy (ACT) played in reducing distress among caregivers of people with dementia. In a study conducted by Han, et al. (2022) the researchers investigated the effects of an online guided Acceptance and Commitment Therapy (ACT) on distressed caregivers (Han et al., 2022). ACT is based on a psychological model involving acceptance (being open to unwanted thoughts and feelings as they occur); cognitive diffusion (detaching from unhealthy thoughts and emotions); being present (mindfulness); observing and reflecting on behaviors (perspective taking); values (connecting one's value set to behaviors); and committed action (aligning one's behaviors with one's values and behaving according to one's value system) (Han et al., 2022). A sample of seven (*n*=7) family caregivers who reported experiencing psychological distress participated in the program. The authors utilized 10 ACT video conference sessions supervised by a trained ACT coach over a 10-week period. The results from the study showed significant reductions in depressive symptoms, anxiety, stress, and caregiver burden at posttest (Han et al., 2022). Further, two main themes emerged from the thematic analysis of the qualitative data, as well as six subthemes (Han et al., 2022).

ACT sessions assisted caregivers in gaining renewed psychological strength by being equipped with the information gained because of the ACT sessions; being more self-compassionate; and exercising patience with the care recipient. Results also indicated that caregivers expressed an understanding of their caregiving journey by acknowledging, observing, and accepting thoughts and feelings as they occurred. By doing so, the caregivers were able to step back from unhelpful thoughts and feelings and engage in less rumination over difficult caregiving situations (Han et al., 2022). Finally, participants reported a renewed ability to engage in value appraisal and value setting goals to engage in a more meaningful life (Han et al., 2022) and increased psychological flexibility because of the ACT intervention. Limitations of the study noted by the researchers included the small sample size, the exploratory nature of the study and the one-group pretest-posttest design.

The data from the present study showed a small to moderate, positive relationship between PCB and mindfulness. In previous studies, mindfulness as a psychological construct was used to measure caregiver burden in numerous contexts, including among caregivers of people with dementia. It is apparent from the foregoing studies that mindfulness and mindfulness-based therapies offer caregivers of people with dementia the opportunity to experience an enhanced quality of life, reduce negative thoughts and emotions that are often associated with caregiving and caregiver burden, and the positive effects of mindfulness-based and Acceptance and Commitment Therapy.

Additionally, data from the extant study showed no statistically significant relationship between years of care recipient’s illness and PCB. Other studies which have sought to determine whether there is a nexus between years of care recipient’s illness and the trajectory of burden have been conducted with mixed results. Connors et al. (2019)

conducted a longitudinal study to investigate levels of PCB over a three-year period and identify predictors of burden. Connors et al. (2019) recruited patients from nine memory care clinics across Australia. Several instruments were employed to determine caregiver burden, the patients' level of cognitive functioning and neuropsychiatric symptoms. Measures were employed at baseline and during regular intervals over a three-year period. Additionally, the researchers recorded patients' level of services and medication usage and changes. The study showed that 47.4% of caregivers had clinically significant levels of burden at baseline and over the course of the three-year period overall levels of burden increased to 56.8%. The lack of data from the present study evidencing no statistical significance between years of care recipient's illness and increased levels of caregiver burden may be accounted for because of the small sample size and the fact that the study did not employ a longitudinal design.

Caregiving in COVID

While the extant study did not consider the influence of locus of control and mindfulness on PCB specifically in the context of the COVID-19 pandemic, the long-term effects of the pandemic cannot be understated or overlooked. These data were collected during the pandemic phase of COVID-19, which thus must be considered in the present context. The deleterious consequences of the worldwide pandemic affected millions of lives. Recent studies addressed the impact of the pandemic on vulnerable populations, including caregivers of people with dementia. In a study conducted by Messina, et al. (2022), the researchers' objective was to explore psychological distress, including caregiver burden and mental wellbeing in caregivers of people with dementia during the first wave of the pandemic. The study included a sample of 571 informal caregivers in Italy and southern Switzerland, two regions severely impacted by the COVID-19 pandemic. The results of the data analysis showed that caregiver burden, anxiety, depressive symptoms, and perceived loneliness were markedly higher among caregivers in these regions. The researchers found that all psychological symptoms, including perceived loneliness were positively correlated to each other and were more pervasive among Swiss caregivers than Italian caregivers, and in spousal caregivers when compared to adult children who cared for a parent or parents. The researchers suggested that regional differences in caregiver burden may have been due to cultural, societal, and contextual circumstances.

Cohen et al. (2020) explored the effects of the COVID-19 pandemic among caregivers of people with dementia and care recipients in Argentina after the initial four weeks of mandatory isolation imposed by the Argentine government. A questionnaire survey was utilized, and the sample comprised 80 family caregivers (*n*=80) of people with Alzheimer’s disease or related dementias. The results of the research showed that confinement because of the pandemic was positively correlated with increased stress and burden, independent of the care recipient’s dementia diagnosis, but those caring for family members with more severe forms of the disease experienced increased stress and caregiver burden. Further, 50% of the care recipients experienced increased anxiety because of mandatory confinement and forced isolation. Additionally, the study evidenced that many caregivers discontinued cognitive and physical therapies for their care recipients, for fear of spreading the disease. Limitations of the study included the small sample size, the lack of a longitudinal follow-up and the lack of instrumentation necessary to measure issues related to caregiver management due to the pandemic, type 1 errors and *p* values were not adjusted for multiple comparisons.

Otobe et al. (2022) investigated changes in caregiver burden during the third wave of the COVID-19 pandemic in Japan. The sample (*n*=700) was comprised of informal caregivers between the ages of 20 and 89 years of age, who had a familial relationship with the care recipient. The researchers explored the factors associated with increased caregiver burden, including depressive symptoms in caregivers, low Barthel Index Scores among care recipients, dementia diagnosis, care days, care times, the use of in-home care services and visiting care service (Otobe et al., 2022). The results from this research showed that 41% of caregivers experienced an increase in burden due to the pandemic (Otobe et al., 2022). The factors associated with increased burden during the pandemic were depressive symptoms, severity of care recipient’s dementia, increased difficulties in engaging in ADLs, care days and times, and the use of home care and visiting care services. The researchers suggested that caregivers who reported increases in caregiver burden were caregivers who reported experiencing depressive symptoms prior to the pandemic, care recipients with dementia, low Bartle Index scores (used to determine care recipient competency in activities of daily living and functional independence), care times and days, and the use of in-home and visiting care services prior to the COVID-19 pandemic (Otobe et al., 2022). The researchers found that a longitudinal causal relationship between the pandemic and increased caregiver burden could not be firmly established (Otobe et al., 2022).

Beach et al. (2021) investigated changes in caregiver burden during the COVID-19 pandemic. The researchers conducted a cross-sectional survey of 576 family caregivers and 2,993 non-caregivers (*n*=3,862) in Pittsburgh, Pennsylvania and through national caregiving website. The outcome measures of the study included psychological distress, sleep disturbance, lower social participation, lower financial well-being, and perceived changes in caregiver burden due to COVID-19. The perceived changes included food insecurity, caregiving contextual variables, and sociodemographic characteristics. There were two overarching issues that the researchers sought to address. The first was a comparison of caregivers and non-caregivers in physical, psychological, social, and financial well-being during the pandemic. The second issue was these groups' perceptions of changes due to the pandemic among family caregivers who were most at risk for adverse social, emotional, physical, and financial effects (Beach et al., 2021). The results of the study showed that family caregivers reported higher anxiety, depression, fatigue, sleep disturbances, lower social participation, lower financial well-being, and increased food insecurities. Caregivers who reported more COVID-related stressors and outcomes reported more adverse outcomes in every domain. Further, the researchers noted that caregivers caring for younger care recipients with emotional, behavioral, or developmental disorders were more susceptible to the adverse effects of the pandemic (Beach et al., 2021).

Hanna et al. (2022) investigated the effects of resiliency and social support on people with dementia and their unpaid caregivers during the COVID-19 pandemic. The researchers employed a qualitative research design and thematic analysis. A sample of 50 unpaid caregivers (*n*=42) and care recipients (*n*=8) were interviewed by telephone to discuss their experiences since the pandemic using in-depth semi-structured interviews (Hanna et al., 2022). The researchers' objectives were two-fold: to assess and explore the different coping strategies and resilience factors used by informal caregivers during the COVID-19 pandemic in response to changes in support services, and to assess lifestyle changes that the caregivers experienced. Additionally, the researchers considered the systemic, social, and individual contextual factors of resilience outside of the context of personality traits (Hanna et al., 2022). After an analysis of the data, four themes emerged. First, effective communication between caregivers and supportive health services appeared to strengthen caregiver resilience. The authors posited that effective communication between outside support services, including healthcare providers was a key factor in improving resilience and reducing caregiver burden. Second, adaptation to digital forms of communication including Skype and Zoom strengthened resilience among caregivers and some care recipients who had previously used digital forms of communication to engage with family members, healthcare professionals, and support services. The authors acknowledged that the use of digital communication acted as a preventative measure against social isolation for the caregiver and offered the care recipient the opportunity to engage with family members while maintaining social distancing and restrictions on in-person contact because of the pandemic. Pre-existing support networks, including family members, healthcare professionals and support services reduced stress, anxiety, and overall burden among the unpaid caregivers. Third, lifestyle factors and coping mechanisms were important factors in reducing caregiver stress. Caregivers and care recipients who engaged in exercise prior to pandemic lockdowns were more likely to continue to engage in exercise as a coping mechanism. This strategy appeared to lessen caregiver stress and burden during the pandemic. Finally, caregivers and care recipients who engaged in social activities prior to the pandemic expressed lower levels of stress and anxiety once lockdowns and government-mandated isolation were in place. The authors posited that people who were highly active, both physically and socially, expressed less anxiety over social distancing restrictions and enhanced resiliency and the ability to cope with government-mandated lockdowns (Hanna et al., 2022).

Canevelli et al. (2020) explored whether the clinical conditions of patients with dementia and other cognitive disturbances changed in the context of the pandemic (Canevelli et al., 2020). A sample of 139 patients enrolled in the Center for Cognitive Disturbances in Rome, Italy participated in a telephone survey administered by medical staff. All participants had been previously diagnosed with dementia or other mild cognitive deficits. The researchers found that cognitive symptoms worsened during the first month of government-mandated lockdowns and that functional independence to engage in personal care and activities of daily living declined among half of the patients. Further, half of the caregivers reported higher levels of stress and exhaustion compared to the previous month (Canevelli et al., 2020). As a result of the data analysis, the researchers concluded that the COVID-19 outbreak adversely affected the clinical conditions of people with dementia and cognitive disturbances (Canevelli et al., 2020), and that caregivers may have been exposed to critical levels of stress because of the lack of external support services and the complex disturbances in the behaviors of their care recipients. The researchers suggested that because of the findings in the study, special supports are needed for cognitively impaired patients and their caregivers during critical events. The researchers suggested that these be designed to monitor the conditions of patients and offer their caregivers the urgently needed supports to minimize stress and enhance at-home care recipient management.

Fong et al. (2021) examined the psychological impact of depression, anxiety, and stress on caregivers of people with dementia in Hong Kong during the COVID-19 pandemic. The sample of 51 caregivers of people with dementia participated in the study at the end of the second wave of the pandemic. The researchers suggested that the coronavirus of 2019 created an atmosphere of fear and apprehension among the residents of Hong Kong. Particularly affected were caregivers of people with dementia because of forced isolation, lockdowns, scarcity of medical and social services, quarantines, the closures of businesses that offered essential supplies such as food, as well as the enormous burden on the then existing healthcare system. An analysis of the data collected showed that caregiver burden and non-attachment were significant predictors of depression. Caregiver burden was also positively correlated with anxiety. The researchers noted that 43 caregivers participated in the follow up survey and these results evidenced that while caregivers experienced less concern over the impact of the pandemic, there were statistically significant decreases in coping efficacy.

Tulloch et al. (2022) examined the experiences of caregivers of people with dementia during the pandemic in Australia. A qualitative research design was employed using semi-structured interviews which were conducted by allied health professionals. The sample consisted of 26 informal caregivers of people with dementia. The researchers separated the data by timeframe to determine prepandemic caregiving experiences, the experiences expressed by caregivers during the pandemic, and postpandemic care considerations. A thematic analysis was conducted, and several themes emerged. Most notably were the positive expressions towards caregiving during the COVID-19 pandemic period of isolation from March through June 2020. Caregivers expressed a greater connection to their core values, reflecting and reassessing the important issues in their lives, the way they viewed themselves, expressions of gratitude, increased patience, personal fortitude, and acts of caring. Prepandemic caregiving appeared focused on the experiences of the care recipient and the supporting care team. Postpandemic expressions included considerations of moving forward with family relationships that were strengthened during the pandemic and the positive aspects of caregiving. The researchers noted that informal caregivers reported the positive aspects related to caregiving during and postpandemic and a renewed sense of self.

Savla et al. (2021) assessed family caregivers’ primary appraisal of stressors related to the government mandated stay-at-home orders during the COVID-19 pandemic, the caregivers’ appraisal of available resources and support services, and the use of coping strategies as predictors of perceived role overload (Savla et al., 2021). The researchers conducted telephone interviews with 53 family caregivers of people with dementia in rural Virginia, two weeks after the government-mandated stay-at-home orders. Caregivers were divided into two groups based on their Role Overload Score. A logistic regression model was employed to examine whether a caregiver’s primary appraisal of the pandemic, secondary appraisal of resources and coping strategies were correlated with higher role overload (Savla et al., 2021). The data showed that caregivers who expressed serious concerns about the pandemic were more vulnerable to poorer psychological well-being due to role overload. Other caregivers expressed fewer concerns about changes to caregiving given that they resided in rural Virginia and lived a solitary lifestyle prior to the pandemic. The researchers suggested that attitudinal differences and caregiver’s perceptions of their experience’s pre-lockdowns were determining factors in increases in role overload.

Marroquin et al. (2020) examined the effects of stay-at-home orders in the context of social distancing, social resources, and mental health during the early stages of the COVID-19 pandemic in February and March 2020. An online sample of 435 adults participated in the research. Of particular interest were the effects of social distancing and the lack of social resources on depression, generalized anxiety disorder, intrusive thoughts, insomnia, and acute stress on the participants. The researchers found that government issued stay-at-home orders and personal distancing behaviors were significantly and independently associated with increase in mental health symptoms (Marroquin et al., 2020). Additionally, the stay-at-home orders were associated with general anxiety disorder, depression, insomnia, and acute stress, but not with intrusive thoughts. Personal distancing behaviors were also associated with higher depression, general anxiety disorder, intrusive thoughts, and acute stress, but not with insomnia. The researchers considered changes in mental health symptoms from February to March 2020 and found that both depression and general anxiety disorder increased.

In a commentary by Hagger et al. (2020), the authors outlined the way stress reappraisals may be a cost-effective and efficacious way to manage stress during and postpandemic to minimize health outcomes. These authors suggested that elevated stress because of lockdowns is likely to continue postpandemic. Elevated stress levels may have long-term health effects such as physical ailments, increases in chronic diseases, and mental health disorders. The authors posited that chronic stress should be considered a long-term public health concern and practitioners are obliged to seek effective remedies post haste. The authors suggested that reappraisal strategies to effect stress management postpandemic may reduce stress related outcomes. Stress appraisals and mindsets are considered central factors in determining whether an individual's response to stress leads to adaptive coping mechanisms or to maladaptive behaviors and ineffective coping as well as compromised health outcomes (Hagger et al., 2020). The authors suggested a two-pronged approach to mitigate stress levels post-pandemic. These approaches include stress reappraisal interventions and a stress-is-enhancing mindset. Central to the stress reappraisal intervention is a focus on how individuals perceive their stress and if stress can be viewed by the individual as a point of convergence where stress is perceived as a beneficial skill to mediate negative stress inducing events (Haggar et al., 2020). The authors further suggested that appraisal strategies can influence an individual's mindset and attitudes towards a stressful event through a reappraisal of both the stressful event and through an acknowledgement that the individual is enabled with emotive skills that allow for the stress to be considered a motivating factor to engage in adaptive behaviors as opposed to maladaptive behaviors. These maladaptive behaviors may lead to poorer behavioral and physical health outcomes (Haggar et al., 2020). The authors suggested that both stress reappraisal and stress-is-enhancing interventions may assist in the management of stress during and after the pandemic (Hagger et al., 2020).

Limitations of the Study

Limitations of this study require consideration. The participants were adult informal caregivers of people with dementia living in the community. Caregivers are tasked with caring for a person with Alzheimer's disease or another form of dementia. In some instances, the caregiver may have become responsible for the daily care of the person with dementia because other family members were unwilling or unable to perform the necessary duties. Further, severity of the disease and type of dementia may also affect the burden experienced by the caregiver. Other factors such as forced isolation, inability to access in-person healthcare, and the suspension of social services including in-home and respite care may also affect the caregiving experience. This study did not consider the full scope of factors that affect PCB. Adult children who provide care to a family member with dementia may have children, a spouse or other familial obligations that require attention. Another factor that this study did not consider was the age of the caregiver, the caregiver's socioeconomic status, or the psychological and somatic strains that are often associated with caregiver burden. The COVID-19 pandemic and individual contextual factors were also not defined in the data collection. While the study has limitations, it is important because it is the first study to explore the combined and relative effects of locus of control and mindfulness on PCB among adult informal caregivers of people with dementia who are living in the community. The sample provided reliable results to establish a solid nexus between mindfulness and its effect on PCB.

Recommendations

The results of this study evidenced that there is no statistically significant relationship between the sociodemographic factors of gender, marital status, occupation and years of care recipient’s illness and PCB. The results did suggest a moderate relationship between education and PCB, where levels of education increased, caregiver burden decreased. This was only marginally significant, however, and not statistically significant at $p < .05$. The results showed no statistically significant relationship between locus of control and PCB. However, the results of the study showed a statistically significant relationship between mindfulness and PCB. As mindfulness increased, PCB decreased. Future studies are needed to address the static nature of PCB and the distal effects of the COVID-19 pandemic on the perceptions of caregivers of people with dementia in the context of subjective burden. Additional research is needed to determine in-group and between group differences between types of caregivers, care recipient dementia diagnosis, and the effects of these factors on PCB.

Future research should consider other factors such as type of employment, caring for other family members in the same setting as the care recipient, the caregiver’s utilization of social and mental health services, and the effects of respite care on PCB. Other factors that should be considered are the long-term somatic and psychological symptoms that may be experienced by informal caregivers in the aftermath of the COVID-19 pandemic and how these factors affect the caregiving experience.

Implications for Professional Practice and Social Change

Healthcare practitioners can utilize the findings to develop and incorporate techniques that promote mindfulness among caregivers of people with dementia. Additionally, the findings may be used to raise awareness and advocate for caregivers of people with Alzheimer’s disease and other forms of dementia. Caregivers play an essential role in society by providing care to people with dementia by shouldering the responsibilities that come with caregiving and relieving much of the stress on an already overburdened healthcare system. As societies age, the number of people who will suffer from dementia will increase and the need for caregivers will also increase. As a result of the cognitive limitations experienced by people with dementia, this segment of the population will continue to rely on family caregivers to thrive. It is essential that frontline health care workers be equipped with interventions to assist caregivers that will improve the quality of life for the caregiver and the care recipient.

Conclusions

The primary objective of this quantitative research study was to examine the influence, if any, of mindfulness and locus of control. The PCB as experienced by informal caregivers of people with dementia. The relationships between mindfulness, locus of control and PCB were analyzed. The results of the study showed that there was no statistically significant relationship between locus of control and PCB. Mindfulness was statistically significant for PCB. While measures were not employed to consider the proximal or distal effects of the COVID-19 pandemic on PCB, the effects of the pandemic on PCB cannot be understated. The results of the study did not show that sociodemographic characteristics of gender, marital status, employment, or years of care recipient's illness were statistically significant on PCB, education showed a slightly significant relationship with PCB, suggesting that higher levels of education reduced PCB. However, the results of the study evidenced a statistically significant relationship with perceived caregiver, suggesting that caregivers who are more mindful experience less caregiver burden. Intensity of PCB may often overwhelm a caregiver, irrespective of the effects of the recent pandemic, and this burden may cause the caregiver difficulties in performing their caregiving role.

As societies age, the number of people suffering from Alzheimer's, dementia or other forms of cognitive impairment will increase, as will the number of people tasked with the role of caregiving. People with dementia will continue to rely on informal caregivers for assistance with activities of daily living as well as to maintain quality of life. It is essential to promote practices to improve the overall quality of life for caregivers and their care recipients while reducing the burden on an overwhelmed and under-resourced healthcare system.

References

Ajay, S., Kasthuri, A., Kiran, P., & Malhotra, R. (2017). Association of impairments of older persons with caregiver burden among family caregivers: Findings from rural South India. *Archives of Gerontology and Geriatrics*, *68*, 143–148. https://doi.org/10.1016/j.archger.2016.10.003

Altieri, M., & Santangelo, G. (2021). The psychological impact of CIVID-19 pandemic and lockdown on caregivers of people with dementia. *America Journal of Geriatric Psychiatry*, *29*(1), 27–34. https://doi.org/10.1016/j.jagp.2020.10.009

Alves, G. S. Casali, M. E., Veras, A. B., Carriho, C. G., Bruno Costa, E., Rodrigues, V. M., & Dourado, M. C. N. (2020). A systematic review of home-setting psychoeducation interventions for behavioral changes in dementia: Some lessons for the COVID-19 pandemic and post-pandemic assistance. *Frontiers in Psychiatry*, *11*, 577871. https://doi.org/10.3389/fpsyt.2020.577871

Alzheimer's Association. (2020). 2020 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, *16*, 32–44. https:www.alz.org/media/Documents/alzheimers-facts and-figures.pdf

Alzheimer's Association. (2021). 2021 Alzheimer's disease facts and figures. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, *17*(3), 327–406. https://doi.org/10.1002/alz.12328

Alzheimer's Association and National Association for Caregiving. (2004). *Families care: Alzheimer's caregiving in the United States 2004*. https://www.caregiving.org/data/alzcaregivers04.pdf

American Psychological Association. (2017). *Ethical principles of psychologists and code of conduct (2002, amended effective June 1, 202, and January 1, 2017)*. https://www.apa.org/ethics/code

Andren, S., & Elmstahl, S. (2008). The relationship between caregiver burden, caregivers' perceived health and their sense of coherence in caring for elders with dementia. *Journal of Clinical Nursing*, *17*, 790–799. https://doi.org/10.1111/j.1365-2702.2007.020666.x

Antonova, E., Schlosser, K., Pandey, R., & Kumari, V. (2021). Coping with COVID-19: Mindfulness-based approaches for mitigating metal health crisis. *Frontiers in Psychiatry, 12*, Article 563417. https://doi.org/10.3389/fpsyt.2021.563417

Archer, J., Reiboldt, W., Claver, M., & Fay, J. (2021). Caregiving in quarantine: Evaluating the impact of the COVID-19 pandemic on adult child informal caregivers of a parent. *Gerontology & Geriatric Medicine*, 7, 1–7. https://doi.org/10.1177/233721421990150

Arnout, B. A., Al-Dabbagh, Z. S., Eid, N. A. A., Eid, M., Al-Musaibeh, S. S., Al-Miqtiq, M. N., Alamri, A., & Al-Zeyad, G. M. (1970, January 1). *[PDF] the effects of Corona virus (COVID-19) outbreak on the individuals' mental health and on the decision makers: A Comparative Epidemiological Study: Semantic scholar*. International Journal of Medical Research and Health Sciences. Retrieved May 6, 2023, from https://www.semanticscholar.org/paper/The-Effects-of-Corona-Virus-%28COVID-19%29-Outbreak-on-Arnout-Al%E2%80%90Dabbagh/202b644143a91c557ac2e37747c04358353acd50

Baer, R. A. (2003). Mindfulness training as a clinical intervention: A conceptual and empirical review. *Clinical Psychology: Science and Practice, 10*(2), 125–143. https://doi.org/10.1093/clipsy/bpg015

Bandura, A. (1969). Social-learning theory of identificatory processes. In D. Goslin (Ed.), Handbook of Socialization Theory and Research (pp. 213-262). Rand McNally & Company.

Bandura, A. (1971). *Social learning theory*. General Learning Press.

Bandura, A. (1973). *Aggression: A social learning analysis*. Prentice-Hall.

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychology Review*, *84*(2), 191–215. https://doi.org/10.1037/0033-295X.84.2.191

Bandura, A. (1991a). Human agency: The rhetoric and the reality. *American Psychologist*, *46*(2), 157–162. https://doi.org/1037/0003-066X.46.2.157

Bandura, A. (1991b). Social cognitive theory of self-regulation. *Organizational Behavior and Human Decision Processes, 50*(2). https://doi.org/10.1016/0749-5978(91)90022-L

Bandura, A. (1994). Self-efficacy. In V.S. Ramachaudran (Ed.), *Encyclopedia of human behavior* (Vol. 4, pp 71-81). New York: Academic Press.

Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York: Freeman.

Band-Winterstein, T., Edelstein, O.E., & Bachner, Y.G. (2019). Correlations of depression in caregivers of ultra-orthodox frail older adults. *American Journal of Orthopsychiatry*, *89*(6): 654-664. https://doi.org/10.1037/ort0000337.

Bascu, J.D.R., O’Connell, M.E., Webster, C., Poole, L., Wighton, M.B., & Sivananthan,

S. (2021). A scoping review of COVID-19 experiences of people living with dementia. *Canadian Journal of Public Health, 112:* 400-411. https://doi.org/10.17269/s1997-021-00500-z.

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

Bergmann, M., & Wagner, M. (2021). The impact of COVID-19 on informal caregiving and care receiving across Europe during the first phase of the pandemic. *Frontiers in Public Health*, *9*: 673874. https://doi.org/10.3389/fpubh.2021.673874.

Bergomi, C., Strohle, G., Michalak, J., Funke, F., & Berking, M. (2013). Facing the dread: Does mindfulness facilitate coping with distressing experiences? A moderator analysis. *Cognitive Behaviour Therapy, 42*(1):21-30. https://doi.org/10.1080/16506073.2012.713391.

Biliunaite, I., Kazlauskas, E., Sanderman, R., & Andersson, G. (2021). Informal caregiver support needs and burden: A survey in Lithuania. *BMJ Open*, 12, Article e054607. https://doi.org/10.1136/bmjopen-2021-054607.

Black, D.S., Sussman, S., Johnson, C.A., & Milam, J. (2012). Psychometric assessment of the Mindful Attention Awareness Scale (MAAS) among Chinese adolescents. *Assessment*, *19*: 42-52. https://doi.org/10p.1177/1073191111415365.

Borges-Machado, F., Barros, D., Ribiero, O., & Carvalho, J. (2020). The effects of COVID-19 home confinement in dementia care: Physical and cognitive decline, Severe neuropsychiatric symptoms and increased caregiving burden. *American*

Journal of Alzheimer's Disease & Other Dementias, 35:1-9. https://doi.org/10.1177/1533317520976720.

Boutoleau-Cretonniere, C., Pouclet-Courtemanche, H., Gillet, A., Bernard, A., Deruet, A.L., Gouraud, I., Mazoue, A., Lamy, E., Rocher, L., Kapogiannis, D., & El Haj, M. (2020a). Impact of confinement on the burden of caregivers of patients with the behavioral variant of frontotemporal dementia and Alzheimer disease during the COVID-19 crisis in France. *Dementia and Geriatric Cognitive Disorders Extra*, 10: 127-134. https://doi.org/10.1159/000511416.

Boutoleau-Cretonniere, C., Pouclet-Courtemanche, H., Gillet, A., Bernard, A., Deruet, A.L., Gouraud, I., Mazoue, A., Lamy, E., Rocher, L., Kapogiannis, D., & El Haj, M. (2020b). The effects of confinement on neuropsychiatric symptoms in Alzheimer's disease during the COVID-19 crisis. *Journal of Alzheimer's Disease*, *76*: 41-47. https://doi.org/10.3233/JAD-200604.

Boyd, J., & Wilcox, S. (2017). Examining the relationship between health locus of control and God locus of health control: Is God and internal or external source? *Journal of Health Psychology*, *25*(7): 931-940. https://doi.org/10.1177/1359105317739099.

Braungart Fauth, E., Femia, E.E., & Zarit, S.H. (2016). Resistiveness to care during assistance with activities of daily living in non-institutionalized persons with dementia: Associations with informal caregivers' stress and well-being. *Aging & Mental Health*, 20(9): 888-898. https://doi.org/1080/13607863.2015.1049114.

Brown, K.W. & Ryan, R.M. (2003a). Mindful Attention Awareness Scale. *Journal of*

Personality and Social Psychology, 84(4): 822-848. https://doi.org/10.1037/00223514.84.4.822.

Brown, K.W., & Ryan, R.M. (2003b). The benefits of being present: Mindfulness and its role in psychological well-being. *Journal of Personality and Social Psychology*, *84*(4): 822-848. https://doi.org/10.1037/0022-3514.84.4.822.

Brown, K.W., & Ryan, R.M. (2004). Perils and promise in defining and measuring mindfulness: Observations from experience. *Clinical Psychology: Science and Practice*, 11(3)242-248. https://doi.org/10.1093/clipsy.bph078.

Budnick, A., Hering, C., Eggert, S., Teubner, C., Suhr, R., Kuhlmey, A., & Gellert, P. (2021). Informal caregivers during the COVID-19 pandemic perceive additional burden: Findings from an ad-hoc survey in Germany. *BMC Health Services Research*, 21: 353. https://doi.org/10.1186/s12913-06359-7.

Canevelli, M., Valletta, M., Blasi, M.T., Remoli, G., Sarti, G., Nuti, F. Sciacalepore, F., Ruberti, E., Cesari, M., & Bruno, G. (2020). Facing dementia during the COVID 19 outbreak. *Journal of the American Geriatrics Society*. Advanced online publication. https://doi.org/10.1111/jgs.16644.

Carballo, J.L., Coloma-Carmona, A., Arteseros-Banon, S., & Perez-Jover, V. (2021). The moderating role of caregiving on fear of COVID-19 and post-traumatic stress symptoms. *International Journal of Environmental Research and Public Health*, *18*(11) 6125-6136. https://doi.org/10.3390/ijerph18116125.

Caregiver burden. (n.d.) *TheFreeDictionary.com*. (2023). Retrieved May 5 2023 from https://www.thefreedictionary.com/caregiver%20burden.

Carlson L.E., & Brown, K.W. (2005). Validation of the Mindful Attention Awareness Scale in a cancer population. *Journal of Psychometric Research*, *58*(1): 29-33. https://doi.org/ 10.1016/j.jpsychores.2004.04.366.

Caserta, M.S., Lund, D.A., & Wright, S.C. Exploring the Caregiver Burden Inventory (CBI): Further evidence for multidimensional view of burden. *International Journal of Aging and Human Development*, *43*(1): 21-34.

Chesak, J. (2020, September 18). Report: How COVID-19 is affecting caregivers. *Very Well Health*. https: www.verywellhealth.com/coronavirus/covid-19-47799524.

Cheung, D.S.K., Kor, P.P.K., Jones, C., Davies, N., Moyle, W., Chien, W.T., King, A.L.K., Chambers, S.M., Yu, C.T.K., & Lai, C.K.Y. (2020). The use of modified mindfulness-based stress reduction and mindfulness-based cognitive therapy program for family caregivers of people living with dementia: A feasibility study. *Asian Nursing Research*, *14*:221-230. https://doi.org/10.1016/j.anr.2020.08.009.

Chiao, C. Y., Wu, H.S., & Hsiao, C.Y. (2015). Caregiver burden for informal caregivers of patients with dementia: A systematic review. *International Nursing Review*, 62(3): 340-350. https://doi.org/10.1111/inr.12194.

Cipolletta, S., Morandini, B., & Tomaino, S.C.M. (2021). Caring for a person with dementia during the COVID-19 pandemic: A qualitative study with family care-givers. *Ageing & Society*, 1-21. https://doi.org/10.1017/S0144686X21000696.

Cohen, G., Russo, M.J., Campos, J.A., & Allegro, R.F. (2020). Living with dementia: Increased level of caregiver stress in times of COVID-19. *International Psychogeriatrics*, *32*(11):1377-1381.

https://doi.org/10.1017/S1041610220001593.

Cohen, S.A., Kunicki, Z.K., Drohan, & Greaney, M.L. (2021). Exploring changes in caregiver burden and caregiving intensity due to COVID-19. *Gerontology & Geriatric Medicine*, *7*:1-9. https://doi.org/10.1177/233372142199279.

Collins, R.N., & Kishita, N. (2019). The effectiveness of mindfulness and acceptance-based interventions for informal caregivers of people with dementia: A meta-analysis. *The Gerontologist*, *59*(4): e363-e379. https://doi.org/10.1093/geront/gny024.

Connors, M.H., Seeher, K., Teixeira-Pinto, A., Woodward, M., Ames, D., & Brodaty, H. (2019). Dementia and caregiver burden: A three-year longitudinal study. *International Journal of Geriatric Psychiatry*, *35*(2): 250-258. https://doi.org/10.1002/gps.5244.

Contador, I., Fernandez-Calvo, B., Palenzuela, D.L., Campos, F.R., Rivera-Navarro, J., & Menezes de Lucena, V. (2015). A control-based multidimensional approach to the role of optimism in the use of dementia daycare services. *American Journal of Alzheimer's Disease & Other Dementias*, *30*(7): 686-693. https://doi.org/10.1177.1533317513494439.

Costello, S., Vaughan, P., & Fahy, S. (2020). Dementia caregiver stress during COVID-19 restrictions survey 2020. *Psychiatry of Later Life 2*. Galway/Roscommon Mental Health Services. https://www.irishpsychiatry.ie/wp-content/uploads/2021/0201.

Cozby, P.C., & Bates, S. (2012). *Methods in Behavioral Research*. NY: McGraw-Hill

Higher Education.

Creswell, J.W. & Creswell, J.D. (2018). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. (5th ed.). Los Angeles, CA: SAGE Publications.

Creswell, J.W. (2009). Research design: Qualitative, quantitative, and mixed methods approach (3rd ed.). Thousand Oaks, CA: SAGE Publications, Inc.

Dalrymple, K.L. & Herbert, J.D. (2007). Acceptance and commitment therapy for generalized social anxiety disorder: A pilot study. *Behavior Modification*, *31*, 543-568. https://doi.org10/1177/0145445507302037.

Deci, E.L. (1971). Effects of externally mediated rewards on intrinsic motivation. *Journal of Personality and Social Psychology*, *18*: 105-115.

Deci, E.L. (1975). *Intrinsic Motivation*. Plenum Press.

Deci, E.L., & Ryan, R.M. (1980). Self-determination theory: When mind mediates behavior. *The Journal of Mind and Behavior*, *1*(1): 33-43. https://www.jstor.org/stable/43852807.

Deci, E.L., & Ryan, R.M. (1985). *Intrinsic motivation and self-determination in human behavior.* Plenum Press.

Deci, E.L. & Ryan, R.M. (2000). The “what” and “why” of goal pursuits: Human needs and the self-determination of behavior. *Psychological Inquiry*, *11*(4): 227-268. https://doi.org/10.1207/S15327965PLI110401.

Deci, E.L., & Ryan, R.M. (2008). Self-determination theory: A macro theory of human motivation, development, and health. *Canadian Psychology*, *49*(3): 182-185. https://doi.org/10.1037/a0012801.

Donald, J.N., Bradshaw, E.L., Ryan, R.M., Basarkod, G., Ciarrochi, J., Duineveld, J.J., Guo, J., & Sahdra, B.K. (2020). Mindfulness and its association with varied types of motivation: A systematic review and meta-analysis using self-determination theory. *Personality & Social Psychology Bulletin*, *46*(7): 1121-1138. https://doi.org/10.1177/0146167219896136.

Druckman, J., Green, D., Kuklinski, J., & Lupia, A. (2011). *Cambridge Handbook of Experimental Political Science*. Cambridge: Cambridge University Press. https://doi.org/10.107/CBO9780511921452.

Duncan, J., & Anderson-Hanley, C. (1998). Dementia caregiver burden: A review of the literature and guidelines for assessment and intervention. *Neurology*, *51*: S53-S60.

Duran-Gomez, N., Guerrero-Martin, J., Perez-Civantos, D., Lopez Jurado, C.F., Palomo-Lopez, P., & Caceres, M.C. (2020). Understanding resilience factors among caregivers of people with Alzheimer’s disease in Spain. *Psychological Research and Behavior Management*, *13*: 1011-1025. https://doi.org/10.2147/PRBM.S274758.

Edwards, N.E., & Scheetz, P.S. (2002). Predictors of burden for caregivers of patients with Parkinson’s disease. *The Journal of Neuroscience Nursing: Journal of the American Association of Neuroscience Nurses*, *34*(4): 184-190. https://doi.org/10.1097/01376517-200208000-00003

Edwards, V.J., Bouldin, E.D., Taylor, C.A., Olivari, B.S., & McGuire, L.C. (2020). Characteristics and health status of informal unpaid caregivers – 44 States, District of Columbia, and Puerto Rico, 2015-2017. *Morbidity and Mortality*

Weekly Report, *69*(7):181-188. https://dx.doi.org/10.15585/mmwr/mm6907a2.

Epstein-Lubow, G., & Armey, M.F. (2011). A pilot investigation of mindfulness-based stress reduction for caregivers of frail elderly. *Mindfulness*, *2*:95-102. https://doi.org/10.1007/s12671-011-0047-4.

Ercoli, L., Gammada, E., Niles, P., & Wyte, Y. (2021). Coping with dementia caregiving stress and burden during COVID-19. *Gerontology & Geriatrics: Research*, *7*(1): 1047-1053.

Family Caregiving Alliance (2022). Caregiver statistics: Work and caregiving. https://www.caregiver.org/resources/caregiver-staistics-work-and-caregiving.

Faul, F., Erdfelder, E., Buchner, A., & Lang, A.-G. (2009). Statistical power analyses using G*Power 3.1: Tests for correlation and regression analyses. Behavior Research Methods, *41:* 1149-1160. https://doi.org/10.3758/BRM.41.4.1149.

Fong, T.K.H., Cheung, T., Chan, W.C., & Cheng, C.P.W. (2022). Depression, anxiety and stress on caregivers of persons with dementia (CGPWD) in Hong Kong amid COVID-19 pandemic. International Journal of Environmental Research and Public Health, *19*: 184-197. https://doi.org/10.3390/ijerph19010184.

Gallagher, A., Li, S., Wainwright, P., Jones, I.R., & Lee, D. (2008). Dignity in the care of older people – a review of the theoretical and empirical literature. *BMC Nursing*, *7*(11). https://doi.org/10.1186/1472-6955-7-11

Gallagher, D., Ni Mhaolain, A., Crosby, L., Ryan, D., Lacey, L., Coen, R.F., Walsh, C., Coakley, D. M., Walsh, B.J., Cunningham, C., & Lawlor, B.A. (2011a). Dependence and caregiver burden in Alzheimer's disease and mild cognitive impairment. *American Journal of Alzheimer's Disease and Other Dementias*, *29*(2): 111-114. https://doi.org/10.1177/1533317510394649.

Gallagher, D., Ni Mhaolain, A., Crosby, L., Ryan, D., Lacey, L., Coen, R.F., Walsh, C., Coakley, D., Walsh, J.B., Cunningham, C., & Lawlor, B.A. (2011b). Self-efficacy for managing dementia may protect against burden and depression in Alzheimer's caregivers. *Aging and Mental Health*, *15*(6): 663-670. https://doi.org/10.1080/13607863.2011.562179.

Gallego-Alberto, L., Losada, A., Cabrera, I., Romero-Moreno, R., Perez-Miguel, A., Pedroso-Chaparro, M.D.S., & Marquez-Gonzalez, M. (2020). "I feel guilty": Exploring guilt-related dynamics in family caregivers of people with dementia. C*linical Gerontologist*. https://doi.org/10.1080/07317115.2020.1769244.

Georgescu, D., Duiu, A., Cheiban, T., Mazilu, T., Rotariu, A., Toma, D., & Baranga, A. (2019). The relationship between locus of control, personal behavior, self-efficacy, and resilience. *Romanian Journal of Cognitive Behavioral Therapy and Hypnosis*, *6*(1-2):1-12.

Gerrig, R.J., & Zimbardo, P.G. (2002). *Psychology and Life*. Allyn and Bacon.

Golinska, P.O., & Obuchowska, A. (2022). Quality of life, severity of burden and sleep disturbances among caregivers of people with dementia. *Neuropsychology*, *17* (1-2):40-48. https://doi.org/10/5114/nan.2022.117955.

Gonyea, J.G., Paris, R., & Zerden, L. (2008). Adult daughters and aging mothers: The role of guilt in the experience of caregiver burden. *Aging and Mental Health*, *12*(5): 559-567. https://doi.org/10.1080/13607860802343027.

Grabel, E., & Adabbo, R. (2011). Perceived burden of informal caregivers of a chronically ill older family member. *The Journal of Gerontopsychology and Geriatric Psychiatry*,*24*(3): 143-154. https://doi.org/10.1024/1662-9647/a000042.

Grau, H., Graessel, E., & Berth, H. (2015). The subjective burden of informal caregivers of persons with dementia: Extended validation of the German language version of the Burden Scale for Family Caregivers (BSFC). *Ageing & Mental Health*, *19*(2): 159-168. https://doi.org/10.1080/13607863.2014.920296.

Greaney, M.L., Kunicki, Z.J., Drohan, M.M., Ward-Ritacco, C.L., Riebe, D., & Cohen, S.A. (2021). Self-reported changes in physical activity, sedentary behavior, and screen time among informal caregivers during the COVID-19 pandemic. *BMC Public Health*, *21*(1):1292-1301. https://doi.org/10.1186/s12889-021-11294-7.

Greenberg, N.E., Wallick, A., & Brown, L.M. (2020). Impact of COVID-19 pandemic restrictions on community-dwelling caregivers and persons with dementia. *Psychological Trauma: Theory, Research, Practice and Policy*, *12*(S1): S220-S221. https://doi.org/10.1037/tra0000793.

Grusec, J.E. (1992). Social learning theory and developmental psychology: The legacies of Robert Sears and Albert Bandura. *Developmental Psychology*, *28*(5): 776-786. https://doi.org/10.1037/0012-1649.28.5.776

Haley, E.E., & Perkins, E.A. (2004). Current status and future directions in family caregiving and aging people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *1*(1), 24-30. https://doi.org/10.1111/j.1741-1130.2004.04004.x

Haley, W.E., & Pardo, K.M. (1989). Relationship severity of dementia to caregiving stress. *Psychology and Aging*, *4*(4): 389-392. https://doi.org/10.1037/0882-7974.4.4.389

Hall, D.L., Millstein, R.A., Luberto, C.N., Perez, G.K., & Park, E.R. (2020). Responding to COVID-19 stress: Disseminating mind-body resiliency approaches. *Global Advances in Health and Medicine*, *9*: 1-4 https://doi.org/10.1177/2164956120976554.

Halse, I., Bjorklof, G.H., Engedal, K., Salbaek, G., & Barca, M.L. (2021). One-year change in locus of control among people with dementia. *Dementia and Geriatric Cognitive Disorders Extra*. *11*: 298-305. https://doi.org/10.1159/000520248.

Han, A., Yuen, H.K., Jenkins, J., & Lee, H.Y. (2022). Acceptance and commitment therapy (ACT) guided online for distressed caregivers of persons living with dementia. *Clinical Gerontologist*, *45*(4): 927-938. https://doi.org/10.1080/073171115.2021.1908475.

Hanley, J.A. (2016). Simple and multiple linear regression: Sample size considerations. *Journal of Clinical Epidemiology*, *79*: 112-119.

Hanna, K., Giebel, C., Butchard, S., Tetlow, H., Ward, K., Shenton, J., Cannon, J., & Komuravelli, A. (2022). Resilience and supporting people living with dementia during the time of COVID-19; A qualitative study. *Dementia*, *21*(1): 250-=269. https://doi.org/10.1177/1471/13012211036601.

Hagger, M.S., Keech, J.J., & Hamilton, K. (2020). Managing stress during the coronavirus disease 2019 pandemic and beyond: Reappraisal and mindset approaches. *Stress Health*, *36*(3): 396-401. https://doi.org/10.1002/smi.2969.

Hartstone, J.M. & Medvedev, O.N. (2021). The role of mindfulness and life satisfaction in psychological distress during the COVID-19 lockdown in New Zealand: A quasi-experimental study. *Mindfulness*, *12*(11): 2693-2706. https:///doi.org/10.1007/s12671-021-01721-4.

Heath, C., Sommerfield, B.S., & von Ungern-Sternberg, B.S. (2020). Resilience strategies to manage psychological distress among healthcare workers during the COVID-19 pandemic: A narrative review. *Association of Anesthetists, 75*(10): 1346-1371. https://doi.org/10.1111/anae.15180.

Hennink, M., Hutter, I., & Bailey, A. (2020). *Qualitative research methods*. (2nd ed.). United Kingdom: SAGE Publications.

Hesse-Biber, S., & Leavy, P. (2011). *The practice of qualitative research.* (2nd ed.). Los Angeles, CA: SAGE Publications.

Holman, H., & Loring, K. (2000). Patients as partners in managing chronic disease. Partnership is a prerequisite for effective and efficient health care. *British Medical Journal*, *320* (7234): 526-527. https://doi.org/10.1136/bmj.320.7234.526.

Hong, M., & Harrington, D. (2016). The effects of caregiving resources on perceived health among caregivers. *Health & Social Work*, *41*(3):155-163/. https://doi.org/10.1093/hsw/hlw025.

Hosseini, S.N., Alavijeh, M.M., Matin, B.K., Hamzeh, B., Ashtarian, H., & Jalilian, F. (2016). Locus of control or self-esteem: Which one is the best predictor of academic achievement in Iranian college students. *Iranian Journal of Psychiatry* *and Behavioral Science*, *10*(10): e2602. https://doi.org/10.17795/ijpbs-2602.

Hsieh, C.C., Yu, C.J., Chen, H.J., Chen, Y.W., Chang, N.T., & Hsiao, F.H. (2018). Dispositional mindfulness, self-compassion, and compassion from others as moderators between stress and depression in caregivers of patients with lung cancer. *Psycho-Oncology*, *28*: 1498-1505. https://doi.org/10.1002/pon.5106.

Huang, M.F., Hui Huang, W., Ching Su, Y., Ying Hou, S., Mei Chen, H., Chun Yeh, Y., & Sheng Chen, C. (2015). Coping strategies and caregiver burden among caregivers of patients with dementia. *American Journal of Alzheimer's Disease & Other Dementias,30*(7): 694-698. https://doi.org/10.1177/1533317513494446.

Iavarone, A., Rosario Ziellao, A., Pastore, F., Fasanaro, A.M., Poderico, C. (2014). Caregiver burden and coping strategies in caregivers of patients with Alzheimer's disease. *Neuropsychiatric Disease and Treatment*, *10*: 1407-1413. https://doi.org/10.2147/NDT.S58063.

Israel, M., & Hay, I. (2006). *Research ethics for social scientists*. London, UK: SAGE Publications.

Judge, T.A., & Bono, E.J. (2001). Relationship of core self-evaluations traits – self-esteem, generalized self-efficacy, locus of control, and emotional stability –with job satisfaction and job performance: A meta-analysis. *Journal of Applied Psychology*, *86*(1): 80-92. https://wwwdoi.org/10.1037/0021-9010.86.1.80.

Kabat-Zinn, J. (2015). Mindfulness. *Mindfulness*, *6*: 1481-1483. https://doi.org/10.1007/s12671-015-0456-x.

Kabat-Zinn, J. (2012). *Mindfulness for beginners: Reclaiming the present moment-and* *your life.* Boulder, CO: Sounds True.

Kabat-Zinn, J. (2003). Mindfulness-based interventions in context: Past, present, and future. *Clinical Psychology: Science and Practice, 10*: 144-156. https://doi.org/10/1093/clipsy.bpg016.

Kabat-Zinn, J. (1994). *Wherever you go, there you are: Mindfulness meditation in everyday life.* Hyperion.

Kabat-Zinn, J. (1993). Mindfulness meditation: Health benefits of an ancient Buddhist practice. In: D. Goleman & J. Garin (Eds)., (pp.257-276). *Mind/Body Medicine*. Yonkers. NY: Consumer Reports.

Kabat-Zinn, J. (1991). *Full catastrophic living: Using the wisdom of your body and mind to face stress, pain, and illness*. New York: Dell Publishing.

Kabat-Zinn, J. (1990). *Full catastrophic living: How to cope with stress, pain and illness using mindfulness meditation*. Bantam Dell.

Kabat-Zinn, J. (1982). An outpatient program in behavioral medicine for chronic pain patients based on the practice of mindfulness meditation. *General Hospital Psychiatry*, *4*(1): 33-47. https://doi.org/10.1016/0163-8343(82)90026-3.

Kabat-Zinn, J., & Burney, R. (1981). The clinical use of awareness meditation in the self-regulation of chronic pain. *Pain, 18*: S273. https://doi.org/10.1016/03043959(81)90541-8.

Karg, N., Graessel, E., Randzio, O., Pendergrass, A. (2018). Dementia as a predictor of care-related quality of life in informal caregivers: A cross-sectional study to investigate differences in health-related outcomes between dementia and nondementia caregivers. *BMC Geriatrics*, *18*: 189. https://doi.org/10.1186/s12877-0180885-1.

Kent, E.E., Ornstein, K.A., & Dionn-Odom, J.N. (2020). The family caregiving crisis meets an actual pandemic. *Journal of Pain & Symptom Management*, *60*(1): e66-e69. https://doi.org/10.1016/j/jpainsymman.2020.04.006.

Kesavayuth, D., Poyago-Theotoky, J., Tran, D.B., & Zikos, V. (2020). Locus of control, health, and healthcare utilization. *Economic Modelling,* 86(C): 227-238. https://doi.org/10.1016.j.econmod.2019.06.014.

Kleitz, M., Drexel, S.C., Schnur, T., Lange, F., Groh, A., Paracka, L., Greten, S., Dressler, D., Hoglinger, G.U., & Wegner, F. (2020). Mindfulness and psychological flexibility are inversely associated with caregiver burden in Parkinson's disease. *Brain Sciences*, *10*(2): 111-121. https://doi.org/10.3390/brainsci10020111.

Kose, B. (2019). Effects of neuroticism and caregiver burden on caregivers' depressive symptoms and well-being: Moderating the role of dispositional mindfulness (Doctoral dissertation, Middle East Technical University).

Kubo, T., Sugawara, D., & Masuyama, A. (2021). The effect of ego-resiliency and COVID-19 related stress on mental health among the Japanese population. *Personality and Individual Differences*, *175*(110702). https://doi.org/10.1016/j/paid.2021.110702.

Kwon, C.Y., Kwak, H.Y., & Kim, J.W. (2020). Using mind-body modalities via telemedicine during the COVID-19 crisis: Case in the republic of Korea.

International Journal of Environmental Research and Public Health, *17*(12): 4477. https://doi.org/10.3390/ijerph17124477.

Kwon, C.Y., & Lee, B. (2021). A protocol for a systematic review and meta-analysis of mind-body modalities to manage the mental health of healthcare workers during the COVID-19 era. *Healthcare*, *9*(10): 1320. https://doi.org/10.3390/healthcare9101320.

Lazarus, R.S., & Folkman, D. (1984). *Stress, appraisal, and coping.* Springer Publishing.

Lee-Kelley, L. (2006). Locus of control and attitudes to working in virtual teams. *International Journal of Project Management*, *24*(3): 234-243. https://doi.org/10.1016/j/ijproman.2006.01.003.

Lethin, C., Renom-Guiteras, A., Zwakhalen, S., Soto-Martin, M., Saks, K., Zabalegui, A., Challis, D.J., Nilsson, C., & Karlsson, S. (2017). Psychological well-being over time among informal caregivers caring for persons with dementia living at home. *Aging & Mental Health*, *21*(11): 1138-1146. https://doi.org/10.1080/13607863.2016.1211621.

Levesque, C., & Brown, K.W. (2007). Mindfulness as a moderator of the effect of implicit motivational self-concept on day-to-day behavioral motivation. *Motivation and Emotion*, *31*: 284-299. https://doi.org/10.1007/s11031-007-9075-8.

Leyland, A.F., Rowse, G., & Emerson, L.M. (2018). Experimental effects of mindfulness inductions on self-regulation: Systematic review and meta-analysis. *Emotion*, *19*(1):108-122. https://doi.org/10.1037/emo0000425.

Li, Q., Zhang, H., Zhang, M., Li, T., Ma., W., An, C., Chen, Y., Liu, S., Kuang, W., Yu, X., & Wang, H. (2021). Mental health multimorbidity among caregivers of older adults during the COVID-19 epidemic. *American Journal of Geriatric Psychiatry*, *29*(7): 687-697. https://doi.org/10.1016/j/jagp.2021.01.006.

Lightfoot, E., & Moone, R. (2020). Caregiving in times of uncertainty: Helping adult children of aging parents find support during the COVID-19 outbreak. *Journal of Gerontological Social Work*, *63*(6-7): 542-552. https://doi.org/10.1080/01634372.2020.1769793.

Lim, J.W., & Zebrack, B. (2004). Caring for family members with chronic physical illness: A critical review of caregiver literature. *Health and Quality of Life Outcomes*, *2*: 50-59. https://doi.org/10.1186/1477-7525-2-50.

Linnehan, M.M. (1993a) *Cognitive-behavioral treatment of borderline personality disorder*. New York, NY: Guilford Press.

Linnehan, M.M. (1993b). *Skills training manual for treating borderline personality disorder*. New York, NY: Guilford Press.

Liu, Z, Chen, AQ.L., & Sun, Y.Y. (2017). Mindfulness training for psychological stress in family caregivers of persons with dementia: A systematic review and meta-analysis. *Clinical Interventions in Aging*, *12*: 1521-1529. https://doi.org/10.2147/CIA.S146213

Liu, Z., Heffernan, C., & Tan, J. (2020). Caregiver burden: A concept analysis. *International Journal of Nursing Sciences, 7*(4): 4380445. https://doi.org/10.1016/j.ijns.2020.07.012.

Liu, S., Li, C., Shi, Z., Wang, X., Zhou, Y., Liu, S., Liu, J., Yu, T., & Ji, Y. (2017). Caregiver burden and prevalence of depression, anxiety and sleep disturbances in Alzheimer's disease caregivers in China. *Journal of Clinical Nursing*, *26*(9-10): 1291-1300. https://dpo.org/10.1111/jocn.13601.

Lorenz-Dant, K., & Comas-Herrera. A. (2021). The impacts of COVID-19 on unpaid carers of adults with long-term care needs and measures to address these impacts: A rapid review of evidence up to November 2020. *Journal of Long-Term Care*, 124-153. https://doi.org/10.31389/jltc.76.

Lyons, J.G., Cauley, J.A., & Fredman, L. (2015). The effect of transitions in caregiving status and intensity on perceived stress among 992 female caregivers and non-caregivers. *Journals of Gerontology: Medical Sciences*, *70*(8): 1016-1023. https://doi.org/10.1093/gerona/glv001.

Macchi, Z.A., Ayele, R., Dini, M., Lamira, J., Katz, M., Pantilat, S.Z., Jones, J., & Kluger, B.M. (2021). Lessons from the COVID-19 pandemic for improving outpatient neuropalliative care: A qualitative study of patient and caregiver perspectives. *Palliative Medicine*, *35*(7): 1258-1266. https://doi.org/10.1177/02692163211017383.

MacLeod, S., Tkatch, R., Kraemer, S., Fellows, A., McGinn, M., Schaeffer, J., & Yeh, C. (2021). The impact of COVID-19 on informal caregivers in the US. *International Journal of Aging Research*, *4*(3): 87-102.

Marit-Moholt, J., Friborg, O., Blix, B.H., & Henriksen, N. (2020). Factors affecting the use of home-based services and out-of-home respite care services: A survey of family caregivers for older persons with dementia in northern Norway.

Marroquin, B., Vine, V., & Morgan, R. (2020). Mental health during the COVID-19 pandemic: Effects of stay-at-home policies, social distancing behavior, and social resources. *Psychiatric Research*, *293*: 113419. https://doi.org/10.1016.j.psychres.2020.113419.

Marsack-Topolewski, C.N., & Church, H.L. (2019). Impact of caregiver burden on quality of life for parents of adult children with autism spectrum disorder. *American Journal on Intellectual and Developmental Disabilities*, *124*(2): 145-156. https://doi.org/10.1352/1944-7558-124.2.145.

Maslow, A.H. (1962). *Toward a Psychology of Being*. New York, NY: Harper & Row Publishers. https://doi.org/10.1037/10793-000.

McLennon, S.M., & N., Lekhak. (2021). “A world upside down”: Experiences of informal caregivers during the COVID-19 pandemic. *Journal of Gerontological Nursing*, *47*(11): 11-14. https://doi.org/10.3928/00989134-20211012-02.

Mercer, D.A., Ditto, B., Lavoie, K.L., Campbell, T., Arsenault, A, & Bacon, S. (2018). Health locus of control is associated with physical activity and other health behaviors in cancer patients. *Journal of Cardiopulmonary Rehabilitation and Prevention*, *28*(6): 394-399. https://doi.org/10.1097/HCR.0000000000000350.

Messina, A., Lattanzi, M., Albanese, E., & Fiordelli, M. (2022). Caregivers of people with dementia and mental health during COVID-19: finding from a cross-sectional study. *BMC Geriatrics*, *22*:56. https://doi.org/10.1186/s12877-022-02752-x.

Ming-Liew, T., Tai, B.C., Yap, P., & Koh, G. C-H. (2019). Contrasting the risk factors of grief and burden in caregivers of persons with dementia: Multivariate analysis. *International Journal of Geriatric Psychiatry*, *34*: 2580264. https://doi.org/10.1002/gps.5014.

Mirzaei, A., Raesi, R., Saghari, S., & Raei, M. (2020). Evaluation of family caregiver burden among COVID-19 patients. *The Open Public Health Journal*, *13*: 808-814. https://doi.org/10.2174.1874944502013010808.

Mochari-Greenberger, H., & Mosca, L. (2012). Caregiver burden and nonachievement of healthy lifestyle behaviors among family caregivers of cardiovascular disease patients. *American Journal of Health Promotion*, *27*(2): 84-89. https://doi.org/10.4278/ajhp.110606-QUAN-241.

National Alliance for Caregiving and AARP. (2009). Caregiving in the U.S.http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf.

National Alliance for Caregiving and AARP. (2020). 2020 Report: Caregiving in the U.S.http://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving in_ the-united-states-01-21.pdf.

Navarta-Sanchez, M.V., Senosiain Garcia, J.M., Riverol, M., Sesma, M.E.U., de Corio Ayesa, S.D., Bravo, S.A., Civera, N.C., & Portillo, M.C. (2016). Factors influencing psychosocial adjustment and quality of life in Parkinson patients and informal caregivers. *Quality of Life Research*, *25*: 1959-1968. https://doi.org/10.1007/s11136-015-1220-3.

Nieto, A., Contador, I., Palenzuela, D.L., Ruisoto, P., Ramos, F., & Fernandez-Calvo, B.

(2022). The distinctive role of grounded optimism and resilience for predicting burnout and work engagement: A study in professional caregivers of older adults. *Archives of Gerontology and Geriatrics*, *100* (104657). https://doi.org/10.1016/j/archger.2022.104657.

Novak, M., & Guest, C. (1989). Application of a multidimensional Caregiver Burden Inventory. *The Gerontologist*, *29*(6): 798-803. https://doi.org/10.1093/geront/29.6.798.

Nowicki, S., Iles-Cavens, Y., Gregory, S., Ellis, G., & Golding, J. (2018). Stability of, and associations between, parent and child locus of control expectancies. *Frontiers in Psychology*, *9* (Article 2018). https://doi.org/10.3389/fpsyg.2018.02018.

Office of Economic Development (2019). *Informal Carers.* In Health at a Glance 2019, OECD Indicators. OECD Publishing. Paris, France.

Ortelli, P., Ferrazzoli, D., Versace, V., Saltuari, L., & Sebastianelli, L. (2021). The need for psychological caregiver-centered intervention in the time of COVID-19. *Alzheimer's & Dementia*, *187*(1): e12166. https://doi.org/10.1002/TRC2.12166.

Otobe, Y., Kimura, Y., Suzuki, M., Koyama, S.M., Kojima, I., & Yamada, M. (2022). Factors associated with increased caregiver burden of informal caregivers during the COVID-19 pandemic in Japan. *J. Nutr. Health Aging*, *26*(2): 157-160. https://doi.org//10.1007/s12603-022-173-y.

Palacio, C.G., Krikorian, A., Gomez-Romero, M.J., & Limonero, J.T. (2020). Resilience in caregivers: A systematic review. *American Journal of Hospice and Palliative*

Medicine, *37*(8): 648-658. https://www.doi.org/10.1177/1049909119893977.

Park, S.S. (2021). Caregivers’ mental health and somatic symptoms during COVID-19. *Journals of Gerontology*, *76*(4): e235-e240. https://doi.org/10.1093/geronb/gbaa121.

Patel, J.O. (2021). Fostering resiliency during the COVID-19 pandemic: Mindfulness and compassion training. *Mindfulness Studies Thesis*, 52. https://digitalcommons.lesley.edu/mindfulness_thesis/52.

Pavalko, E.K. (2011). Caregiving and the life course: Connecting the personal and the public. In R. Settersten & Angel, J. (Eds.), *Handbook of Sociology and Aging* (pp.603-616). Springer. https://www.doi.org/10.1007/978-1-4419-7374-0_37.

Pearlin, L.I., Mullan, J.T., Semple, S.J., & Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist*, *30*(5): 583-594. https://doi.org/10.1093/geront/30.5.583.

Pfefferbaum, B., & North, C.S. (2020). Mental health and the COVID-19 pandemic. *The New England Journal of Medicine*, *383*(6): 510-512. https://doi.org/10.1056/NEJMp2008017.

Pinquart, M., & Sorenson, S. (2003). Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *Journal of Gerontology: Psychological Sciences*, *58B*(2): 112-128. https://doi.org/10.1093/geronb/58.2.P112.

Pinquart, M., & Sorensen, S. (2007). Correlates of physical health of informal caregivers: A meta-analysis. *Journal of Gerontology: Psychological Sciences*, *62B*(2): P126 -

P137.

Polenick, C.A., Lei L., Zhou, A.N., Birditt, K.S., & Maust, D.T. (2021). Caregiver status and illness self-efficacy during the COVID-19 pandemic among older adults with chronic conditions. *Aging & Mental Health*, 1-7. Advance online publication. https://doi.org/10.1080/13607863.2021.1901260.

Pongan, E., Dorey, J-M., Borg, C., Getenet, J.C., Bachelet, R., Lourioux, C., Laurent, B., COVCARE Group, Rey, R., & Rouch, I. (2021). COVID-19: Association between increase of behavioral and psychological symptoms of dementia during lockdown and caregivers' poor mental health. *Journal of Alzheimer's Disease*, *80*(4): 1713-1721. https://doi.org/10.3233/JAD-201396.

Proulx, C.M., & Snyder, L.A. (2009). Families and health: An empirical resource guide for researchers and practitioners. *Family Relations*, *58*(4): 489-504. https://doi.org/10.1111/j.1741-3729.2009.00568.x.

Punch, K. (2005). *Introduction to social research: Quantitative and qualitative approaches.* (2nd ed.). London, UK: SAGE

Rathier, L.A., Davis, J.D., Papandonatos, G.D., Grover, C., & Tremont, G. (2015). Religious coping in caregivers in family members with dementia. *Journal of Applied Gerontology*, *34*(8): 977-1000. https://doi.org/10.1177/0733454813510602.

Robison, J., Fortinsky, R., Kleppinger, A., Shugrue, N., & Porter, M. (2009). A broader view of family caregiving: Effects of caregiving and caregiver conditions on depressive symptoms, health, work, and social isolation. *Journal of Gerontology:*

Social Sciences, *64B*(6): 788-798. https://www.doi.org/10.1093/geronb/gbp015.

Rodrigues, R., Simmons, C., Schmidt, A., Steiber, N. (2021). Care in times of COVID-19: The impact of the pandemic on informal caregivers in Austria. *European Journal of Ageing*, *18*: 195-205. https://doi.org/10.1007/s10433-021-00611-z.

Rotter, J. (1982). *The development and applications of social learning theory*. New York: Praeger.

Rotter, J.B. (1975). Some problems and misconceptions related to the construct of internal versus external control of reinforcement. *Journal of Consulting and Clinical Psychology*, *43*: 56-67.

Rotter, J. (1966). Generalized expectancies for internal versus external control of reinforcement. *Psychological Monographs: General and Applied*, *80*(1), (Whole 609): 1-28. http://dx.doi.org/10.1037/h002976.

Rotter, J. (1954). *Social learning and clinical psychology*. New York: Prentice-Hall. https://doi.org/10.1037/10788-0000.

Rotter, J.B., & Hochreich, D.J. (1975). *Personality*. Scott Foresman.

Ruisoto, P., Contador, I., Fernandez-Calvo, B., Serra, L., Jenaro, C., Flores, N., Ramos, F., &Rivera-Navarro, J. (2020). Mediating effect of social support on the relationship between resilience and burden in caregivers of people with dementia. *Archives of Gerontology and Geriatrics*, *86*: 103952. https://doi.org/10.1016/j.archger.2019.103952.

Russell, B.S., Hutchison, M., Tambling, R., Tomkunas, A.J., & Horton, A.L. (2020). Initial challenges of caregiving during COVID-19: Caregiver burden, mental health and the parent-child relationship. *Child Psychiatry & Human Development*, *51*: 671-682. https://doi.org/10.1007/S10578-020-01037-x.

Ryan, R.M. (1995). Psychological needs and the facilitation of integrative processes. *Journal of Personality*, *63*(3); 397-427. https://doi.org/10/1111/j.1467-6494.1995.tb00501.x

Ryan, R.M. (2005) The developmental line of autonomy in the etiology, dynamics, and treatment of borderline personality disorder. *Development and Psychopathology*, *7*(4): 987-1006. https://doi.org/10.1017/S095445794050504 67.

Ryan, R.M., Huta, V., & Deci, E.L. (2008). Living well: A self-determination theory perspective on eudaimonia. *Journal of Happiness Studies*, *9*: 139-170. https://doi.org/10.1007/s10902-006-9023-4.

Savla, J., Roberto, K.A., Blieszner, R., McCann, B.R., Hoyt, E., & Knight, A.L. (2021). Dementia caregiving during the "Stay-at-Home" phase of COVID-19 pandemic. *The Journals of Gerontology: Series B*, *76*(4): e241-e245. https://doi.org/10.1093/geronb/gbaa129

Savundranayagam, M.Y., Montgomery, R.J.V., & Kosloski, K. (2011). A dimensional analysis of caregiver burden among spouses and adult children. *The Gerontologist*, *51*(3): 321-331. https://doi.org/10.1093/geront/gnq012.

Schultz, P.P., & Deci, R.M. (2015). The "why," "what," and "how" of healthy self-regulation: Mindfulness and well-being from a self-determination theory perspective. In B.D. Ostafin, M.D. Robinson, & B.P. Meier (Eds.), *Handbook of Mindfulness and Self-Regulation* (pp. 81-94). New York: Springer.

https://doi.org/10.1007/978-1-4939-2263

Schulz, R., & Sherwood, P.R. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing*, *108*(9 Suppl):23-27. https://doi.org/10.1097/01.NAJ.0000336406.45248.4c.

Senturk, S.G., Akyol, M.A., & Kucukguclu, O. (2018). The relationship between caregiver burden and psychological resilience in caregivers of individuals with dementia. *International Journal of Caring Sciences*, *11*(2): 1223-131, https://www.internationaljournalofcaringsciences.org/docs/66_kucukguclu_original_10_2 pdf.

Shaw, W.S., Patterson, T.L., Semple, S.J., Grant, I., Yu, E.S.H., Zhang, M.Y., He, Y., & Wu, W.Y. (1997). A cross-cultural validation of coping strategies and their associations with caregiving distress. *The Gerontologist*, *37*(4): 490-504. https://doi.org/10.1093/geront/37.4.490.

Sirgy, M.J. (1986). A quality-of-life theory derived from Maslow's developmental perspective. *The American Journal of Economics and Sociology*, *45*(3); 329-342. https://doi.org/10p.1111/j.1536-7150.1986.tb02394.x.

Sivasubramoney, K., & Lekshmy, K. (2020). Mindfulness for professional caregivers of coronavirus disease-19-positive patients – A realistic need of the hour. *International Journal of Nursing*, *6*(4): 120-124. https://doi.org/10.31690.ijnr.2020.v06i04.001.

Slack, D.M. (1985). *The effects of self-perception and locus of control on coping behavior: A study of caregivers of Alzheimer's patients.* PhD dissertation. Texas

Tech University.

Southwick, S.M., & Charney, D.S. (2012). The science of resilience: Implications for the prevention and treatment of depression. *Science*, *338*(6103): 79-82. https://doi.org/10.1126/science.1222942.

Spillers, R.L., Wellisch, D.K., Kim, Y., Matthews, B.A., & Baker, S. (2008) Family caregivers and guilt in the context of cancer care. *Psychosomatics*, *49*: 511-519. https://doi.org/10.1176/appi.psy.49.6.511.

Tan, G.T.H., Yuan, Q., Devi, F., Wang, P., Ng, L.L., Goveas, R., Chong, S.A., & Subramaniam, M. (2021). Factors associated with caregiving self-efficacy among informal caregivers of persons with dementia in Singapore. *BMC Geriatrics*, *21*(13). https://doi.org/10.1186/s12877-020-01951-8.

Tan, K.P., Ang, J.K., Koh, E.B.Y., Pang, N.T.P., & Saher, Z.M. (2023). Relationship of psychological flexibility and mindfulness to caregiver burden, and depressive and anxiety symptoms in caregivers of people in dementia. *International Journal of Environmental Research and Public Health*, *20*: 4232. https://doi.org/10.3390/ijerph20054232.

Tan-Ho., G.M., Choo, P.Y., Patinadan, P.V., Low, C.X., & Yan Ho, A.H. (2020). Blessings or burdens: An interpretative phenomenological analysis (IPA) study on the motivations and their impact on end-of-life caregiving among Asian family caregivers. *BMC Palliative Care*, *19*: 132-142. https://doi.org/10.1186/s12904-020-00638-6.

Teehan, A., Lafferty, A., Fealy, G.M., McAuliffe, E., Phelan, A., O’Sullivan, L., &

O'Shea, D. (2016). An evidence synthesis of resilience in dementia caregiving: A systematic review. *Age and Ageing*, *45*(supp_2): 1-12. https://doi.org/1093/ageing/afw159.31.

Todorovic, N., Vracevic, M., Rajovic, N., Pavlovic, V., Madzarevic, P., Cumic, J., Mostic, T., Milic, N., Rajovic, T., Sapoic, R., Milcanovic, P., Velickovic, I., Culafic, S., Stanisavljevic, D., & Milic, N. (2020). Quality of life of informal caregivers behind the scenes of the COVID-19 epidemic in Serbia. *Medicina*, *56*: 647-657. https://doi.org/10.3390/medicina56120647.

Tsai, C-F, Hwang, W-S, Lee, J-J, Wang, W-F, Huang, L-C, Huang, L-K, Lee, W-J, Sung, P-S, Liu, Y-C, Hsu, C-C, & Fuh, J-L. (2021). Predictors of caregiver burden in aged caregivers of demented older patients. *BMC Geriatrics*, *21*: 59. https://doi.org/10.1186/s12877-021-02007-1.

Tulloch, K., McCaul, T., & Scott, T.L. (2022). Positive aspects of dementia caregiving during the COVID-19 pandemic. *Clinical Gerontologist*, *45*(1): 86-96. https://doi.org/10.1080/07317115.2021.1929630.

Vaitheswaran, S., Lakshminarayanan, M., Ramanujam, V., & Sargunan, S. (2020). Experiences and needs of caregivers of persons with dementia in India during the COVID-19 pandemic – A qualitative study. *American Journal of Geriatric Psychiatry*, *28*(11): 1185-1194. https://doi.org/10.1016/j.jagp.2020.06.026.

van der Heide, A., Meinders, M.J., Bloem, B.R., & Helmich, R.C. (2020). The impact of the COVID-19 pandemic on psychological distress, physical activity, and symptom severity and Parkinson's disease. *Journal of Parkinson's Disease*, *10*(4): 1355-1364. https://doi/org.10.3233/JPD-202251.

Vitaliano, P.P., Young, H.M., & Russo, J. (1991). Burden: A review of measures using among caregivers of individuals with dementia. *The Gerontologist*, *31*(1): 67-75. https://doi/org.10.1093/geront/31.1.67.

Vitaliano, P.P., Zhang, J., & Scanlan, J.M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, *129*(6): 946-972. https://doi/org.10.1037/0033-2909.129.6.946.

Wang, G., Tan, X., & Zheng, W. (2017). The moderating effect of dispositional mindfulness on the relationship between materialism and mental health. *Personality and Individual Differences*, *107*: 1310136. https://doi.org/10.1016/j.paid.2016.11.041.

Weinstein, N., Brown, K.W., & Ryan, R.M. (2009). A multi-method examination of the effects of mindfulness on stress attribution, coping, and emotional well-being. *Journal of Research in Personality*, *43*(3): 374-385. https://doi.org/10.1016.j.jrp.2008.12.008

Weisman de Mamani, A., Weintraub, M.J., Mauro, J., Martinez de Andino, A., & Brown, C. (2018). The interplay among mindfulness, caregiver burden, and mental health in family members of individuals with dementia. *Professional Psychology: Research and Practice*, *49*(2): 116-123. https://doi.org/10.1037/pro0000181.

Whitebird, R.R., Kreitzer, M., Crain, A.L., Lewis, B.A., Hanson, L.R., & Enstad, C.J. (2012). Mindfulness-based stress reduction for family caregivers: A randomized controlled trial. *The Gerontologist*, *53*(4): 676-686.

https://doi.org/10.1093/geront/gns126.

Widha, L., Rahmat, H.K., & Hasan Basri, A.S. (2021). A review of mindfulness therapy to improve psychological well-being during the Covid-19 pandemic. *Proceeding: International Conference on Science and Engineering*, *4*: 383-386. http://sunankalijaga.org/prosiding/index.php/icse/article/view/693.

Wiegelemann, H., Speller, S., Verhaert, L.M., Schirra-Weirich, L., & Wolf-Ostermann, K. (2021). Psychosocial interventions to support the mental health of informal caregivers of persons living with dementia – A systematic literature review. *BMC Geriatrics*, *21*:94. https://doi/org.10.1186/s12877-021-02020-4.

Williams, F., Moghaddam, N., Ramsden, S., & DeBoos, D. (2019). Interventions for reducing levels of burden amongst informal carers of persons with dementia in the community: A systematic review and meta-analysis of randomized controlled trials. *Aging& Mental Health*, *23*(2): 1629-1642. https://doi.org/10.1080/13607863.2018.151886.

World Health Organization (2021, September 3). *Dementia*. https://www.who.int/news-room/fact-sheets/detail/dementia.

Yu, H., Wang, X., He, R., Liang, R., &Zhou, L. (2015). Measuring the caregiver burden of caring for community-residing people with Alzheimer's disease. *PLoS One*, *10*(7): e0132168-e0132181. https://doi/org.10.1371/jourmnal.pone.0132168.

Zucca, M., Isella, V., Di Lorenzo, R., Marra, C., Cagnin, A., Cupidi, C., Bonanni, L., Lagana, V., Rubino, E., Vanacore, N., Agosta, F., Caffarra, P., Sambati, R., Quaranta, D., Gugliemi, V., Appollonio, I., Logroscino, G., Filippi, M., Tedeschi, G., Ferrarese, C., Rainero, I., Bruni, A.C., & the SINderm COVID-19 Study Group. (2021). Being the family caregiver of a patient with dementia during the Coronavirus Disease 2019 lockdown. *Frontiers in Aging Neuroscience*, *13*: Article 653533. https://doi/org.10.3389/fnagi.2021.653533.

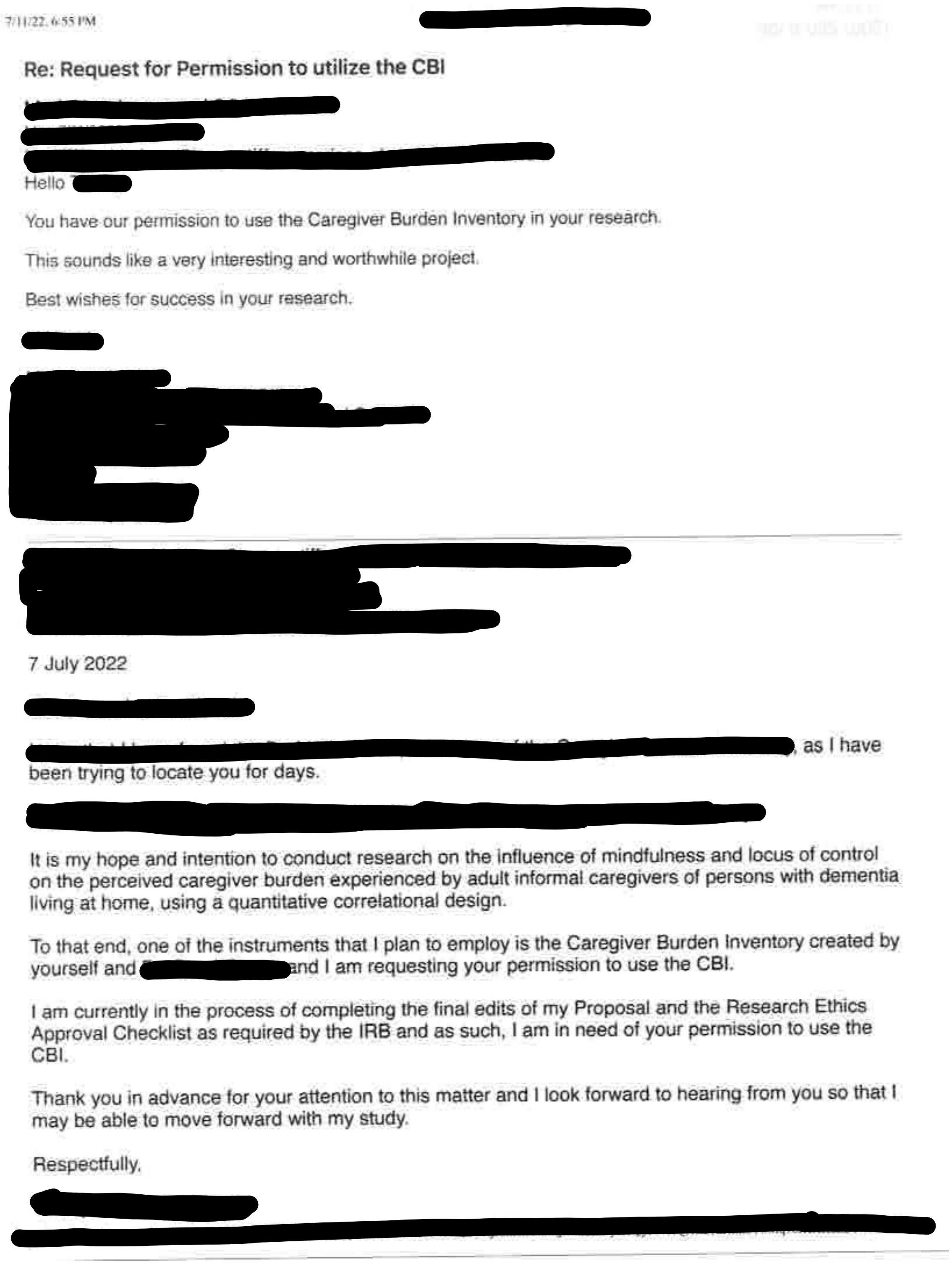
Appendix A: Recruit Participant Online Ad

Would you like to take part in a research study about providing care to persons with dementia?

- Studies have shown that caregivers of persons with dementia experience unique challenges and may expertise varying levels of burden.
- Your participation in this study may help others understand the daily challenges faced by caregivers.
- To participate in the study, you must be age 18 years and older, provide (unpaid) care to a person or persons with dementia or Alzheimer's and the person receiving care must live in the community (at home).
- You will be asked to complete 3 surveys that may take up to 45 minutes to complete.
- All survey data will be collected anonymously to protect your privacy.

If interested in participating in this study, please contact: [redacted] student at Walden University at: [redacted] or by confidential email at: [redacted]

Appendix B: Permissions to Use Instruments in Research



7/11/22, 6:55 PM [redacted]

Re: Request for Permission to utilize the CBI

[redacted]

Hello [redacted]

You have our permission to use the Caregiver Burden Inventory in your research.

This sounds like a very interesting and worthwhile project.

Best wishes for success in your research.

[redacted]

[redacted]

[redacted]

7 July 2022

[redacted]

[redacted], as I have been trying to locate you for days.

[redacted]

It is my hope and intention to conduct research on the influence of mindfulness and locus of control on the perceived caregiver burden experienced by adult informal caregivers of persons with dementia living at home, using a quantitative correlational design.

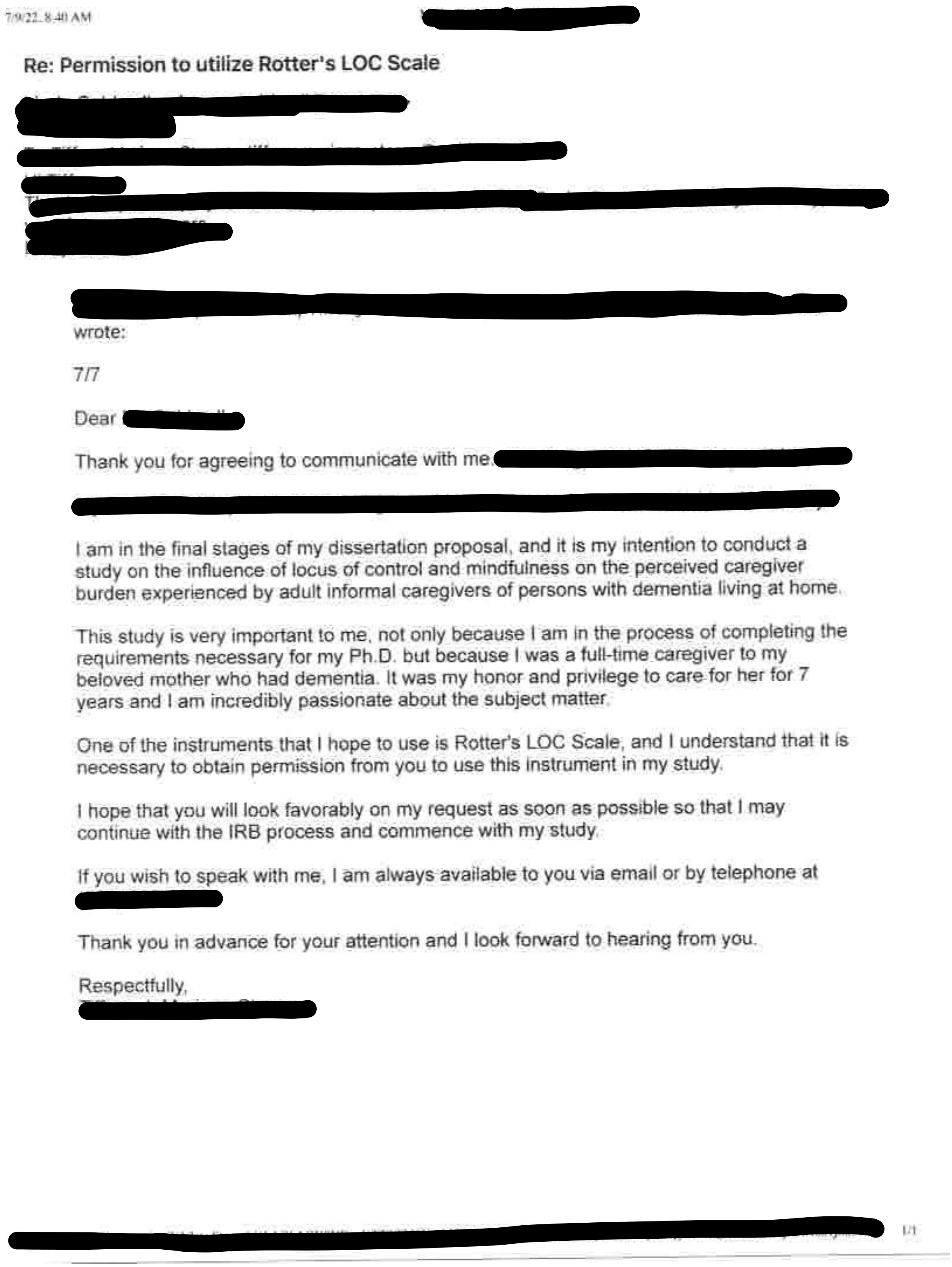
To that end, one of the instruments that I plan to employ is the Caregiver Burden Inventory created by yourself and [redacted] and I am requesting your permission to use the CBI.

I am currently in the process of completing the final edits of my Proposal and the Research Ethics Approval Checklist as required by the IRB and as such, I am in need of your permission to use the CBI.

Thank you in advance for your attention to this matter and I look forward to hearing from you so that I may be able to move forward with my study.

Respectfully,

[redacted]



7/9/22, 8:40 AM [redacted]

Re: Permission to utilize Rotter's LOC Scale

[redacted]

[redacted]

wrote:

7/7

Dear [redacted]

Thank you for agreeing to communicate with me [redacted]

[redacted]

I am in the final stages of my dissertation proposal, and it is my intention to conduct a study on the influence of locus of control and mindfulness on the perceived caregiver burden experienced by adult informal caregivers of persons with dementia living at home.

This study is very important to me, not only because I am in the process of completing the requirements necessary for my Ph.D. but because I was a full-time caregiver to my beloved mother who had dementia. It was my honor and privilege to care for her for 7 years and I am incredibly passionate about the subject matter.

One of the instruments that I hope to use is Rotter's LOC Scale, and I understand that it is necessary to obtain permission from you to use this instrument in my study.

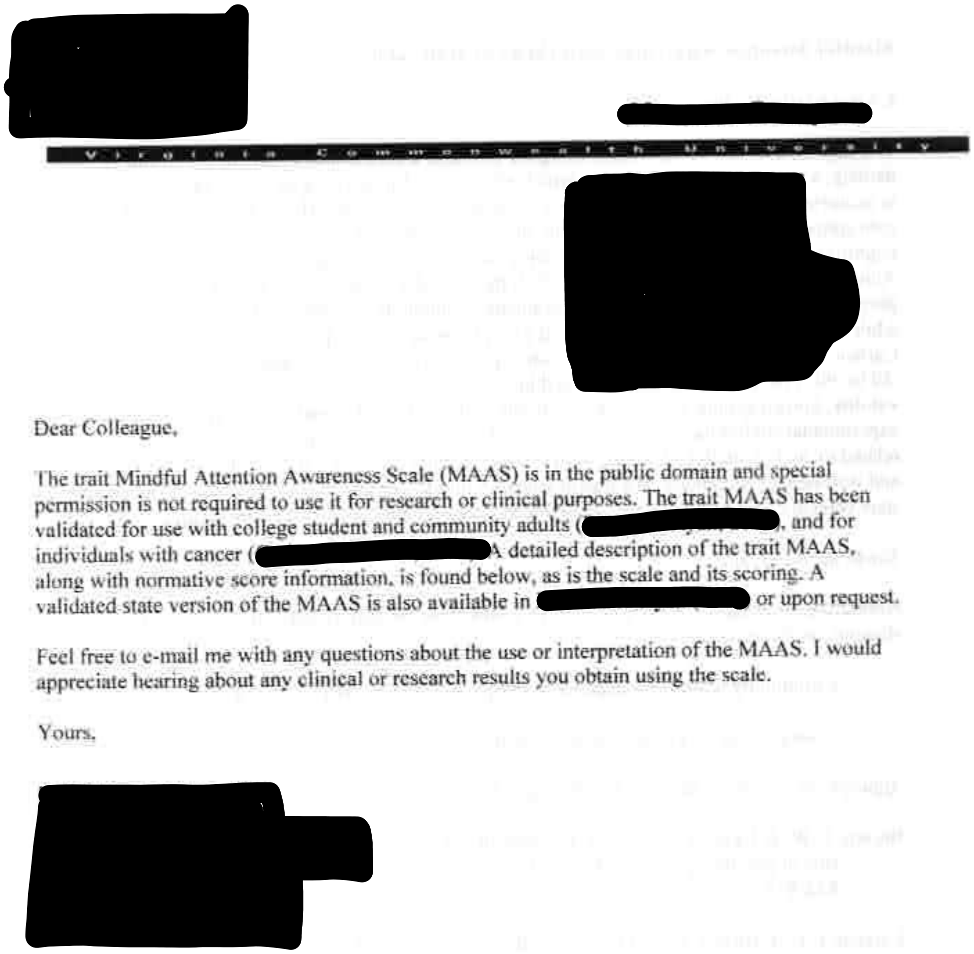
I hope that you will look favorably on my request as soon as possible so that I may continue with the IRB process and commence with my study.

If you wish to speak with me, I am always available to you via email or by telephone at [redacted]

Thank you in advance for your attention and I look forward to hearing from you.

Respectfully,
[redacted]

[redacted] 1/1



[redacted]

[redacted]

Virginia Commonwealth University

[redacted]

Dear Colleague,

The trait Mindful Attention Awareness Scale (MAAS) is in the public domain and special permission is not required to use it for research or clinical purposes. The trait MAAS has been validated for use with college student and community adults ([redacted], and for individuals with cancer ([redacted] A detailed description of the trait MAAS, along with normative score information, is found below, as is the scale and its scoring. A validated state version of the MAAS is also available in [redacted] or upon request.

Feel free to e-mail me with any questions about the use or interpretation of the MAAS. I would appreciate hearing about any clinical or research results you obtain using the scale.

Yours,

[redacted]