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2020

Rethinking Burnout in Informal Caregivers: Development and Validation of The Informal Caregiver Burnout Inventory - 10 Item Form

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RETHINKING BURNOUT IN INFORMAL CAREGIVERS:
DEVELOPMENT AND VALIDATION OF THE
INFORMAL CAREGIVER BURNOUT INVENTORY – 10 ITEM FORM

by

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M.S. University of Central Florida, 2019

A dissertation submitted in partial fulfillment of the requirements
for the degree of Doctor of Philosophy
in the Department of Psychology
in the College of Sciences
at the University of Central Florida
Orlando, Florida

Fall Term
2020

Major Professor: Daniel Paulson

ABSTRACT

Measurement of informal caregiver burnout is typically achieved by re-purposing scales of occupational burnout. Such approaches have several methodological and theoretical weaknesses. This paper proposes a new tool for measuring caregiver burnout: The Informal Caregiver Burnout Inventory (ICBI). In the first portion of this study, focused feedback was collected from within-field experts and caregivers. Following item revision, an online sample of informal US caregivers of an individual with dementia was collected. Item Response Theory analysis was used to prune low-information or low-consistency items from the scale. The finalized ICBI contained 10 items and showed strong convergent validity, adequately differentiated burnout from depression, and had high internal reliability. The ICBI was compared against two gold-standard measures of occupational burnout and was able to satisfactorily correlate burnout with subjective and objective burden, perceived support, depressive symptoms, and intent to transfer to long-term care services. Auxiliary hypotheses assessed the use of burnout as a moderator and mediator in the relationship between burden and depression and intent to transfer to long-term care services. Burnout was found to significantly moderate the relationship between burden and depression but did not moderate the relationship between burden and intent to transfer. Similarly, burnout partially mediated the relationship between burden and depression but did not mediate intent to transfer. The ICBI is a powerful, lightweight, and accessible measure of burnout for informal caregivers of individuals with dementia. Recommendations for future applications of the ICBI, future avenues of research, and utility of the scale are discussed.

ACKNOWLEDGMENTS

This dissertation is in dedication to my family, loved ones, peers, and mentors who have made decades of preparation for this endeavor possible. To my parents who taught me to be unreasonably persistent, thank you for never hesitating to support my pursuits. For my mentor, Dr. Daniel Paulson, thank you for welcoming me into your lab, revitalizing my passion for inquiry, and helping shape my career trajectory. And to the many mentors I have had that have modeled integrity, ingenuity, and compassion, without your efforts I would not be the researcher and clinician I am today. Finally, to my significant other and my closest friends, I am endlessly thankful for the numerous moments you have encouraged me, been excited by my excitement in research, and made balancing life and vocation possible. Max De Pree is quoted with the saying, "We cannot become what we need to be by remaining what we are." I cannot express the gratitude I feel for those in my life who have encouraged, advised, and inspired as I forged ahead; I dedicate this dissertation to all of you.

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CHAPTER 1: INTRODUCTION

Burnout was first conceptualized as a means to explain workplace attrition for healthcare professionals or those in burdensome working environments (Freudenberger, 1975; C Maslach, 1976). Since the 1970s, the concept of burnout has been extensively studied and has become colloquially used across the world. Despite nearly five decades of research, burnout has only recently been included in diagnostic manuals such as the revised International Classification of Diseases version 10 (ICD-10) as a diagnosable condition exclusively related to occupational stressors (World Health Organization, 2018). Since the inception of burnout, there has been a proliferation of research attempting to explain why burnout occurs, the numerous health and organizational consequences surrounding burnout, and means to prevent or reverse it (Alarcon, Eschleman, & Bowling, 2009; Purvanova & Muros, 2010; Schaufeli & Maslach, 2017; West, Dyrbye, Erwin, & Shanafelt, 2016). During this period of empirical study, there were schisms in theory concerning how to best conceptualize burnout. Each developing theory of burnout incorporated novel subdomains that were thought to satisfactorily embody the phenomena. This diversity in definitions has led to debate as to which conceptualization best represents the latent construct (Bianchi, Schonfeld, & Laurent, 2015). A common theme among these theories of burnout, however, is the notion that burnout represents physical, mental, and emotional exhaustion (Kristensen, Borritz, Villadsen, & Christensen, 2005).

As a construct, burnout is a valuable mechanism to understand the experiences of those who engage in difficult, time-consuming, and physically or emotionally taxing endeavors. For this reason, the concept of occupational burnout has often been extended to research of informal caregivers. Within this research, burnout has been associated with greater burden, lower levels of

social support (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Almberg, Grafström, & Winblad, 1997; Kasuya, Polgar-Bailey, & MPH Robbyn Takeuchi, 2000; Truzzi et al., 2012), and undesirable outcomes such as depression and premature transfer to long-term care services (Mittelman, Haley, Clay, & Roth, 2006; Takai et al., 2009; Yaffe et al., 2002). The measurement of burnout within informal caregivers has historically been accomplished using modified occupational burnout questionnaires where terms such as "work" have been replaced with "caregiving" and "client" has been exchanged with "care recipient" (e.g., Angermeyer, Bull, Bernert, Dietrich, & Kopf, 2006). No known research has yet to validate the use of these modified questionnaires, and no measure of burnout specific to informal caregivers is known to exist. This study evaluates the use of a novel scale of burnout created for informal caregivers of an individual with Alzheimer's or other dementia-related impairment.

Current Conceptualizations of Burnout

The intent of this study is not to overturn the established theories of burnout, but to adapt existing conceptualizations to best fit the unique population that is dementia caregivers. Of note, both articles that initially proposed the concept of burnout were written from the perspective of health service professionals (Freudenberger, 1975; C Maslach, 1976); thus, these theories already account for many experiences found within the caregiving dynamic from a professional perspective. For example, Freudenberger (1975) stated that burnout is often the result of a person overcommitting, being excessively dedicated, and ultimately overextending an individual's own emotional well-being for the benefit of others. This sentiment has been echoed by many informal caregivers experiencing burnout (Kasuya et al., 2000; Lee & Singh, 2010; Takai et al., 2009).

Over the years, few researchers have offered a generalizable conceptualization of burnout capable of being applied outside of the human service industry or general occupational setting. Therefore, while burnout is increasingly recognized as an existent and detrimental phenomenon, it has only recently been recognized as a diagnosable condition within the ICD-10 criteria (World Health Organization, 2018).

Presently, few studies attempting to account for burnout draw clear lines between variables contributing to burnout and factors making up the dimensions of the latent construct of burnout, leading to debate and inconsistent findings across studies (Schaufeli & Maslach, 2017). One framework which clearly conceptualizes burnout separately from its causal factors is the job demands-resources (JD-R) model (Bakker & Demerouti, 2007; Demerouti, Bakker, Nachreiner, & Schaufeli, 2001). This model was originally created to account for burnout in any occupational setting, not just the human service industry. Demerouti et al. (2001) proposed a two-factor model of burnout comprising of high occupational demands and limited job resources. Within the JD-R model, job demands refer to physical, psychological, or social costs associated with work-related tasks that are not necessarily negative or detrimental (Bakker & Demerouti, 2007). Demand is theorized to increase as the frequency, intensity, and duration of high-cost tasks increase. Conversely, job resources refer to aspects of the work-environment that reduce costs, stimulate growth, or are rewarding. Ultimately, an imbalance in these occupational demands and resources will lead to undesirable outcomes such as poor work quality, health impairment, and attrition (Bakker & Demerouti, 2007; Hakanen, Bakker, & Demerouti, 2005; Xanthopoulou, Bakker, Demerouti, & Schaufeli, 2007). Since the inception of the JD-R model, a clearer and more complex understanding of this model has been uncovered through a proliferation of research on

the topic (Bakker and Demerouti, 2016). Specifically, concepts such as personal resources, motivation, strain, self-undermining, gain spirals, and other special considerations have been integrated into the theory and are discussed by Bakker and Demerouti (2016) in an update article. Most notable of the advances in the JD-R model is consideration of the role of the individual, their pre-existing resources, and their distinctive response style to demands and resources (Bakker & Demerouti, 2016). By understanding the complex interaction of role demands and resources on an individual, one can begin to better understand both undesirable (e.g., exhaustion, health complaints, or anxiety) and desired (e.g., motivation, engagement, or commitment) outcomes.

Though the JD-R was created with the goal of generalizing the theory of burnout to any occupation, it inadvertently offers a model that can be applied to informal caregivers. Previous research has found that caregiving burden is inversely related to positive aspects of caregiving (C. A. Cohen, Colantonio, & Vernich, 2002; Hilgeman, Allen, DeCoster, & Burgio, 2007), perceived social support (Haley, Levine, Brown, & Bartolucci, 1987; Thompson Jr, Futterman, Gallagher-Thompson, Rose, & Lovett, 1993), and access to professional services (Gaugler, Kane, Kane, & Newcomer, 2005; Peeters, Van Beek, Meerveld, Spreeuwenberg, & Francke, 2010; Sussman & Regehr, 2009). Considering these findings, burnout should moderate the relationship between caregiving demands and resources (i.e., burden) and undesirable caregiving outcomes (i.e., depression or transfer to long-term care). However, as of today, this relationship has not been empirically studied within dementia caregivers. While this study represents the first efforts to create and validate a measure of burnout for dementia caregivers, it also represents an opportunity to advance research on the role of burnout within this population. Following the

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creation of the proposed measure of burnout, this study examines the relationship between burden and undesirable outcomes as moderated by burnout within dementia caregivers. One possible alternative understanding of the role of burnout in the relationship between burden and undesirable caregiving outcomes is that of a mediating variable. In such a case, burnout may function as a mechanism creating undesirable caregiving outcomes. While it has been well established that burden is related to such outcomes, it is the case that not all caregivers experiencing high levels of burden experience depression or transfer to long term care services. Burnout may offer an explanation for this incongruent finding.

Application of Burnout to Caregivers

Informal caregivers are an enormously heterogeneous group who make up a significant portion of the population. Recent samples estimate that there are 34.2 million informal caregivers within the US, 46% of whom care for recipients with dementia-related difficulties (NAC & AARP, 2015). These caregivers provide 234 billion dollars' worth of care each year (CBO, 2013). The older adult population is constantly growing and expected to consist of over 80 million individuals by the year 2050. Considering the relative limits to current healthcare infrastructure, informal caregivers provide an invaluable service by reducing utilization of professional care services (CBO, 2013; Charles & Sevak, 2005; Ortman, Velkoff, & Hogan, 2014). Consequently, efforts made to reduce both caregiver burden and premature transfer to long-term care services is a central goal of many caregiving support interventions.

Measures of burnout contain assumptions based on the populations they were constructed to assess. As the current gold-standard measures of burnout are concerned with the occupational

setting, the way in which the latent variable of burnout is captured incorporates assumptions relevant to the workplace. For example, the Copenhagen Burnout Inventory (CBI) was originally created to measure burnout within service industry workers; therefore, it contains subscales related to personal-, work-, and client-related burnout (Kristensen et al., 2005). While scales of occupational burnout have been modified and used to measure burnout within informal caregivers (e.g., Takai et al., 2009; Truzzi et al., 2012), these scales have yet to be validated for use within the informal caregiving population. Importantly, it is possible these occupational measures will function sufficiently within the informal caregiver population, although such studies have yet to be conducted. In such a case, while measurement of burnout may be valid, the unique circumstances of informal caregivers must still be attended to when attempting to understand protective factors, onset, and various impacts of burnout within this population.

Professional caregiver (e.g., physicians, nurses, mental-health aids) burnout has been extensively studied since it was the first population in which burnout was recognized. While we can use this as a foundation in adapting burnout to informal caregivers, there exist fundamental structural, role, and task differences between the two groups. For example, a professional caregiver may assist several clients with Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs; e.g., Appendix H), or medical/nursing tasks during their shift. Dementia caregivers are often untrained in the medical/nursing tasks they engage in (79%); further, they often care for a single relative (88%), including spouses (12%) who require forty or more hours of care per week (26%; NAC & AARP, 2015). Given these fundamental role differences, factors theorized to contribute to occupational burnout (e.g., workload, control, reward, community, fairness, and values; Christina Maslach, Schaufeli, & Leiter, 2001) need to

be re-conceptualized. Factors not included in original occupational burnout models (e.g., filial obligation, disease severity, living circumstances, role strain, and caregiver preparedness), which are known to relate to burden or burnout, need to be considered in informal caregivers.

Within the population of informal caregivers exists a subset of people who provide care for an individual with Alzheimer's or other dementia-related diseases. Samples of dementia caregivers often highlight the dissimilarities to other informal caregivers. For example, the 2015 Caregivers in the US study (Hunt, Whiting, Baumgart, Weber-Raley, & Panek, 2017) found dementia caregivers are often older and taking care of older care recipients. With respect to caregiving duties, dementia caregivers were found to provide a greater number of IADLs and ADLs as well as more frequent intimate activities such as incontinence, bathing, and eating. Further, informal dementia caregivers are significantly more likely to assist with healthcare management, advocacy, and monitoring/adjusting treatment for advancing medical conditions. Finally, dementia caregivers often provide care more hours per week. With respect to burden, dementia caregivers report higher overall burden, report more frequent and severe physical and mental health impacts, and are more often required to reduce work hours, quit their jobs, or retire early. Importantly, dementia is a degenerative disorder with no existing cure. Therefore, dementia caregivers are often providing care for longer periods of time and have increasingly difficult emotional and caregiving demands as the disease progresses (Haley & Pardo, 1989; Hunt et al., 2017). While burnout was not assessed in this sample, dementia caregivers were more likely to report feeling unprepared for their role, request more support from professional caregivers, and often wish to receive help managing their own personal stress (Hunt et al., 2017).

Premature transfer to long-term care facilities is a notoriously difficult outcome to measure. Certainly, the use of professional care services can be an appropriate decision depending on an individual's care needs (E. A. Miller, Allen, & Mor, 2008), especially when medical care is unavailable in the home setting. However, due to the societal, personal quality of life, and financial benefits related to prolonging the time until an individual is transferred, this construct is often the focus on caregiving research and interventions. It has been established that older adults with access to informal care are able to forego transfer to long-term care services longer than those without a care network (B. Miller & Furner, 1994; Stoller & Pugliesi, 1988). Transfer can be prevented by assistance with a few ADLs (e.g., dressing, bathing, or feeding), IADLs (e.g., shopping, cleaning the home, preparing food), or medical/nursing tasks. Therefore, by reducing burnout and enabling caregivers to provide more assistance, long-term care transfer can be prevented (e.g., Luppa et al., 2009; Mittelman et al., 1993). There are a plethora of documented factors contributing to care transfer, including lack of time due to child-care responsibilities, work obligations, financial burden, lack of caregiver training/support, and overall caregiver burden (Allen, Lima, Goldscheider, & Roy, 2012; Gaugler, Yu, Krichbaum, & Wyman, 2009; B. Miller & Furner, 1994; Verbeek et al., 2015). There has been extensive research on the topic of care recipient-related factors associated with care transfer. Thorough review of the literature revealed that these variables most commonly influence transfer: incontinence, motor disturbance, mental disorientation, living alone, and general needs for more intensive care or general worsening of symptoms (Branch & Jette, 1982; Buhr, Kuchibhatla, & Clipp, 2006; Gaugler, Mittelman, Hepburn, & Newcomer, 2009; Luppa et al., 2009; Risco et al., 2015; Verbeek et al., 2015). Given that burnout theoretically represents the variance in an

individual's exhaustion and likelihood to attrite (transfer to long-term care) based on overall

burden, the proposed measure of informal caregiver burden will serve as an important tool in

identifying high-risk caregivers most in need of support. Of note, burnout does not

spontaneously remit once care transfer occurs (Gaugler, Mittelman, et al., 2009; Gaugler, Roth,

Haley, & Mittelman, 2008; Mittelman et al., 1993), and the continual monitoring of caregiver

burden and burnout are warranted across care settings and level of caregiver involvement.

Unique to informal caregiver burnout is the relationship dynamic between a caregiver and

care recipient. Most informal caregivers are married or related to the care recipient. Thus,

attachment and familial obligation must also be considered when capturing burnout. Various

lines of research have found attachment and filial obligation as protective factors in informal

caregiver burden (Braun et al., 2009; Crispi, Schiaffino, & Berman, 1997; Magai & Cohen,

1998). This attachment is further complicated when role strain or role conflict occurs. Role strain

is the phenomena in which an individual must divide attention and time between several societal

roles (e.g., wife, daughter, caregiver, mother, employee), whereas role conflict occurs when

expectations of two roles are incompatible or tremendously difficult to maintain (e.g., working

full time while providing care full time; Mui, 1992). These role-based stressors must be

considered as another potential factor related to burden and burnout in the lives of many

caregivers. Various studies have documented the relationship between role-based stressors and

occupation, familial, romantic, and social role impacts (Covinsky et al., 2001; Edwards, Zarit,

Stephens, & Townsend, 2002; Mui, 1992; Siegel, Raveis, Houts, & Mor, 1991; Wilson, Van

Houtven, Stearns, & Clipp, 2007). Given this study is one of the first attempts to validate a

measure of burnout for dementia caregivers, attempts were made to replicate previous findings associating role conflict with burden and burnout.

Proposed Buffers to Caregiver Burnout

Perhaps the most apparent differences between informal caregiving and employment are the organizational environment and structure. This is to say, employment entails co-workers, bosses, corporate support/guidelines, agreed-upon work hours, contracts, vacation, and even sick days. These do not directly map onto the construct of burnout, yet they may contribute to the buffering or intensifying of burnout similar to environmental resilience factors. By and large, much of the structure professional caregivers benefit from simply does not exist for informal caregivers. Parallels to some structural support factors may exist. For example, informal caregivers may be able to take "breaks" or even "days off" by utilizing friend/family support or professional care services. Community support and professional service utilization are recognized as playing an important role in burnout reduction for informal caregivers (Cooper & Marshall, 1976; Finney, Stergiopoulos, Hensel, Bonato, & Dewa, 2013; Wang, Liu, & Wang, 2015; Yong & Yue, 2007). While reconceptualizing burnout within informal caregivers, special attention should be paid to these buffering factors known to correlate with burden, such as social support (Thompson Jr et al., 1993), perceived support (Chiou, Chang, Chen, & Wang, 2009; Haley et al., 1987), and professional service utilization (Etters, Goodall, & Harrison, 2008; Magliano et al., 2002; Reinhard, 1994). Various measures of occupational burnout consider environmental and structural factors. Similarly, the proposed scale will include a supplementary measure of social support, professional support, and perceived utility of these supports. This

section will not directly contribute to burnout scores but will allow for an initial examination of the role perceived support plays in relation to burnout.

<div align="center">Theoretical Considerations of Exhaustion within Caregivers</div>

Exhaustion is typically represented by physical, mental, and emotional impacts resulting from work that is emotionally or physically draining, time-consuming, and without an end in sight (Freudenberger, 1975; Schaufeli & Greenglass, 2001). The more difficult and ceaseless the work, the greater the impact on work quality (Laschinger, Shamian, & Thomson, 2001; Linzer et al., 2009; Van Bogaert, Kowalski, Weeks, & Clarke, 2013), quality of life (Takai et al., 2009), and eventually attrition (Federici & Skaalvik, 2012). This study measured physical, mental, and interpersonal exhaustion to account for the latent construct of burnout. While exhaustion manifests differentially for each person, global impairment should be expected due to the close relationship between a person's physical, mental, and interpersonal well-being. For example, a caregiver who is experiencing physical exhaustion (e.g., fatigue, loss of appetite, sleeplessness) may feel more irritable around friends/family or may even avoid social engagements due to somatic symptoms. Early research into the manifestation of burnout supported this global perspective of exhaustion impact (Christina Maslach, Jackson, Leiter, Schaufeli, & Schwab, 1986). Each individual's insight into which areas of functioning have been impaired may differ. For example, someone may more easily identify frequent illnesses compared to mood changes or reduced social engagement. Therefore, assessing each area of functioning will result in a more sensitive instrument able to detect burnout within a more diverse population. Finally, impairment in one area may result in a domino effect of impairment across settings (e.g., lack of social

engagement results in feelings of isolation and loss of motivation, which leads to further lack of

social engagement and lack of access to social support).

When an individual says they "feel exhausted," this often reflects the more common

colloquial uses of the term burnout. This experience of mental or emotional exhaustion often

involves feeling "at wit's end," emotionally drained, hopeless, unable to persist, or the experience

of avolition. One may recognize an overlap between descriptors of burnout and depression. Over

the years, this similarity has led to a strong and widely replicated correlation between the two

constructs. Unsurprisingly, this pairing has also been a topic of debate for decades. Some

researchers have argued depression and burnout are one-in-the-same (Bianchi, Boffy, Hingray,

Truchot, & Laurent, 2013), while others have argued they are two distinct concepts (Bakker et

al., 2000; Brenninkmeyer, Van Yperen, & Buunk, 2001), or that both concepts account for a

portion of a larger undefined phenomenon (Ahola et al., 2005). Recent reviews of this subject

conclude this commonality is the result of two factors: the lack of precise and consistent

operationalization of burnout and the considerable heterogeneity of depressive symptoms

(Bianchi et al., 2015). It should be noted that most measures of burnout contain their own unique

sub-scales such as emotional exhaustion, depersonalization, personal accomplishment,

satisfaction, disengagement, exhaustion, and work-place, client-related, and personal burnout

(Demerouti, Mostert, & Bakker, 2010; Kristensen et al., 2005; Christina Maslach et al., 1986).

Therefore, criticisms of inconsistent measurement of burnout are inevitable. As discussed earlier,

despite the high number of auxiliary subdomains, most researchers agree exhaustion is a central

construct of burnout (Kristensen et al., 2005). The proposed study will represent the latent

construct of burnout from the perspective of exhaustion alone. It is expected there will be a

correlation between symptoms of depression and burnout. While an important topic, this study

will not attempt to further address the debated relationship between burnout and depression.

<u>Prospective, Downstream Outcome Variables</u>

Symptoms of physical exhaustion include not only the physiological experience of

fatigue but psychosomatic and medical symptoms. For example, Freudenberger (1975) notes

exhaustion and fatigue may manifest as headaches, gastrointestinal disturbances, weight loss,

sleeplessness, and a weakened immune system resulting in increased frequency or intensity of

illnesses. Nationwide health studies have found burnout is associated with increased prevalence

of musculoskeletal disease in women and cardiovascular disease in men after controlling for

health behaviors, depression, and socioeconomic factors (Honkonen et al., 2006). Further,

physical symptoms of burnout such as sleep disturbance, bodily pain, and self-reported physical

exhaustion have served as useful tools in discriminating between those experiencing burnout

from those experiencing only disengagement from work (Peterson et al., 2008). Keeping these

physical indicators of burnout in mind, the proposed scale utilizes exhaustion related to self-care,

physical fatigue/lethargy, and frequent illness as indicators the physical manifestation of

exhaustion.

Social engagement often requires the use of physical, psychological, and scheduling

resources. For example, those who feel sick, fatigued, unmotivated, or simply lack time are less

likely to engage in enjoyable social activities. While this disengagement may conserve resources

initially, it has been well-documented that social engagement can serve as a buffer to stressors

(Cohen, 2004) and play an important role in the maintenance of physical and mental well-being

(Kawachi & Berkman, 2001). Further, social support and perceived social support have been shown to play an important role in reducing caregiver burden (Chiou et al., 2009; Rodakowski, Skidmore, Rogers, & Schulz, 2012), improving well-being (Kaufman, Kosberg, Leeper, & Tang, 2010; Webb et al., 1998), and influencing better overall outcomes (Haley et al., 1987). Research on this topic has found that caregivers of frail older adults benefit the most from certain types of social support, such as recreational and enjoyable social activities (Thompson Jr et al., 1993).

A fundamental dynamic that differentiates dementia caregiving burden from occupational burden is the relationship between the caregiver and care recipient. In many circumstances, caregivers are providing parents or spouses with self-care and nursing needs, tasks most people never consider performing. Experiencing conflict while navigating the transition between caregiver and loved one has been associated with increased perception of burden and may put tremendous strain on the relationship (Adams, 2006; Gaugler, Kane, & Newcomer, 2007; Marks, Lambert, & Choi, 2002; Morris, Morris, & Britton, 1988; Schumacher, 1995). Taking into consideration how the deterioration of this relationship may reflect a caregiver's overall fatigue and exhaustion, the proposed scale includes questions assessing anger and irritability directed at the care recipient and enjoyment of time spent together.

Burnout, while characterized in many fashions across the literature, is fundamentally representative of an individual's exhaustion and fatigue, typically in response to strenuous, time-consuming, and persistent burden. The proposed measure of burnout stratifies exhaustion into three domains of fatigue: physical, emotional, and social. Each of these domains of exhaustion has been previously linked to burnout; therefore, the proposed measure should have good sensitivity and specificity to capture the breadth and depth of burnout a caregiver may

experience. Scales assessing perceived social support, resilience, and burden exist for informal caregivers, yet no scale of burnout has been created or adapted and validated for this population. Given that burnout is associated with depression, other mental/physical health consequences, and attrition, quantifying and accurately capturing this construct within the population of dementia caregivers will offer an invaluable tool to any healthcare professional working with these caregivers. This study has two goals: 1) to construct and validate a novel scale of caregiver burnout, and 2) to identify the degree to which burnout influences the relationship between burden and undesirable caregiving outcomes among community-dwelling dementia caregivers in the US.

CHAPTER 2: METHODS

Scale Construction and Validation

This study employed several best practices in scale development and validation as suggested by Boateng, Neilands, Frongillo, Melgar-Quiñonez, and Young (2018). 1) The domains of physical, mental, and social exhaustion were chosen after a thorough review of the available literature on dementia caregiver burnout. Where studies including dementia caregivers were unavailable, the literature search was first expanded to any informal caregivers followed by professional caregivers. 2) Items were generated using a "classification from above" or deductive method in which the relevant literature was used to generate items that were hypothesized to represent the constructs of interest (Hinkin, 1995). To allow for future item pruning, potentially redundant or conceptually broad questions were included in the initial version of the Informal Caregiver Burnout Inventory (ICBI; Appendix B). Response options were set to a 5-point Likert-type scale, which is thought to offer optimal response reliability (Krosnick, 2018). Initial item review was performed using expert evaluation and target population feedback. 3) The expert evaluation entailed item-by-item evaluation where within-field experts judged each item as appropriate and interpretable. Cohen's coefficient kappa was used to measure inter-rater agreement between experts, and items were included, excluded, or modified based on feedback (eg., Augustine et al., 2012). 4) Target population evaluation entailed sampling a small number of dementia caregivers. These caregivers rated items on acceptability and clarity. Similar to expert evaluation, the scale was modified based on this feedback.

Following initial scale construction efforts, a final full sample of informal caregivers was collected online. 5) Item reduction analysis was used in an effort to remove items with poor

item-total correlations (polychoric correlations); items showing poor inter-domain correlations (r < .30) were tagged for deletion or modification (Boateng et al., 2018). The final step in initial scale development was the assessment of latent variable modeling using confirmatory factor analysis. While analytic methods capable of accounting for both unidimensional and multidimensional latent factors exist (Reise, Moore, & Haviland, 2010), this study did not utilize them, as there is no theoretical need to account for other domains aside from burnout. 6) Scale reliability was established using Cronbach's alpha within subdomains and the full scale. 7) Convergent validity was examined by comparing the ICBI against two gold-standard measures of occupational burnout, the Copenhagen Burnout Inventory (CBI; Kristensen et al., 2005) and the Oldenburg Burnout Inventory (OLBI; Demerouti et al., 2010). These scales were compared using T-tests followed by evaluation of a Bland-Altman Plot to determine the degree of agreement (e.g., Giavarina, 2015). Given their shared theoretical background, a high correlation between these scales was expected. 8) Divergent validity was examined by comparing the ICBI against a common measure of depression, the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977). Divergent validity was measured using the same analytic procedures as convergent validity.

This study seeks to develop a measure of burnout better suited to assess caregiver burnout than currently established measures of occupational burnout. Therefore, 9) predictive validity was assessed by comparing the relationship between measures of burnout (ICBI, CBI, OLBI) and previously identified outcomes of end-stage burnout, specifically depression and intent to transfer the care recipient to long-term care. Further, as the preventative nature of social support on burnout is one of the more well-documented relationships within caregiving literature,

predictive validity was further assessed by evaluating the existence and strength of a negative correlation between social support and burnout as measured by the ICBI. 10) The importance of controlling for social desirability bias is becoming increasingly recognized as an important step in self-report scale development (King & Bruner, 2000; Van de Mortel, 2008). Therefore, the ICBI was tested for social desirability response bias by assessing the correlation between burnout and participants' scores on the Social Desirability Scale-17 (SDS-17; Stöber, 2001).

To ensure optimal scale construction, the ICBI was evaluated using principles of Item Response Theory (IRT). IRT represents an assortment of statistical approaches purposed with estimating the connection between items or surveys and the latent constructs that they are attempting to quantify (De Ayala, 2013). Initially, IRT was created with dichotomous measurement in mind; however, the proposed study utilizes ordered polytomous, Likert-style questions to represent burnout along a continuum. The graded response model (GRM) was devised to evaluate items that use graded or Likert-style responses (e.g., school letter grades or scores on aptitude tests) to capture latent constructs of interest (De Ayala, 2013; Koch, 1983). As part of the GRM approach, item threshold parameters were calculated to assess the point at which a participant is more likely to respond to a certain response option of higher compared to lower scale choices. For example, within the ICBI, a GRM provided item-by-item probabilities of when a participant is likely to respond to each Likert-anchor or higher (e.g., agree completely through disagree completely). Using this approach, each item within the ICBI was mapped on a distribution to determine how and at what point they map onto the spectrum of burnout. This metric acts as a difficulty parameter that can then be used to prune redundant or low-utility items. Finally, an overall task information function was calculated for the ICBI, OLBI, and CBI

subscales. The task information function represents the breadth and depth of information captured by the entire questionnaire. This function contains the sum of information captured by each item, which is then graphed onto a bell-shaped curve; higher peaks of this curve indicate a greater quantity of information captured by the sum of items whereas a greater width of this curve indicates a larger spectrum of the latent variable being captured (i.e., floor and ceiling effects; Baker & Kim, 2004). While these graphs are traditionally compared visually, for the purpose of measurement comparison, an average score for the test information functions was calculated and compared.

<u>Study Participants</u>

This study includes a sample of informal caregivers currently assisting in the needs of a care recipient experiencing dementia or dementia-related difficulties. An individual was defined as a "dementia caregiver" if they met the operational criteria of providing unpaid care for a friend, relative, or loved one to aid/supplement Activities of Daily Living (ADLs) and/or Instrumental Activities of Daily Living (IADLs). Participants were recruited through the Amazon Mechanical Turk (MTurk) service, online forums, and community support organizations. Those participating via the Amazon Mechanical Turk service were monetarily compensated for their participation. Other participants who chose to contribute through online forums and community groups were informed of the Mechanical Turk option, but compensation was not be accessible otherwise. Participants were excluded from the study if they did not meet the above criteria as a "dementia caregiver," they were under the age of 18, live outside of the United States, or were unable to comprehend English. The full survey included questions meant

to check for participant attention and prevent low-quality responses. A participant's data was excluded if they did not respond correctly to these fidelity questions.

Proposed Sample Size

There are a variety of sample size recommendations to consider for scale development and validation. The desired sample size for this proposed study was 300 dementia caregivers. For initial measure construction, a 2-5 participants-per-item ratio with a minimum size of 100 is considered best practice (Anthoine, Moret, Regnault, Sébille, & Hardouin, 2014). The initial version of the ICBI contains 25 questions, therefore a sample of 300 informal caregivers meets the above criteria. Of note, this study includes a moderation analysis which requires a sample size of 220 participants to capture small-to-medium effect sizes (f2 = 0.05, power 0.8, alpha 0.05; Faul, Erdfelder, Buchner, & Lang, 2009; Soper, 2015). Additionally, this study utilizes a confirmatory factor analysis for which a sample size of 200-300 is suggested as appropriate to test a theoretical model via a Monte Carlo Analyses (Muthén & Muthén, 2002; Myers, Ahn, & Jin, 2011). A recent review of the Monte Carlo approach suggests the necessary upper limit of a sample size would be 460 participants, should more complex modeling be necessary (Wolf, Harrington, Clark, & Miller, 2013). Of note, IRT-related analyses such as calculating item threshold parameters may require a sample of 500 individuals to provide optimal parameter estimates (Jiang, Wang, & Weiss, 2016). Given the difference between recommended sample sizes and the presumed maximum sample size feasible to be collected for this study, IRT analyses were underpowered. This limitation was considered during analysis.

<center>Measures</center>

Caregiver Screener*:* Participants were asked three questions regarding their age, caregiving status, and the diagnosis of the care recipient. Questions assessing care recipient diagnosis covered a wide range of possible medical conditions. The first purpose of this screener was to identify individuals who fit the study criteria listed above. The second purpose of the screener was to control for possible low-quality or insincere respondents via the Mechanical Turk survey system. Once participants are confirmed to meet inclusion criteria they were funneled into the main survey.

Demographic Variables*:* Common demographic variables were collected including, basic demographic information (i.e., gender, ethnicity, age) and idiographic information (i.e., education, marital status, number of children, employment, and income/socioeconomic status).

Caregiver Circumstance*:* Participants were asked several questions to assess their caregiving involvement: ADLs, IADLs, medical/nursing tasks, hours per week providing care, years spent caregiving, relationship to the care recipient, and plans to transfer to long-term care services. Caregiver circumstance and burden questions are listed in Appendix A.

<center>**Assessment Measures**</center>

<u>Caregiving Burden</u>*:* Participants completed the Level of Care Index (National Alliance for Caregiving, 2005, 2009; National Alliance for Caregiving (NAC) and AARP Public Policy Institute, 2015; Persons, 1997). The Level of Care Index contains several questions which assess the number of ADLs and IADLs performed by the caregiver and hours spent providing care each week. Additionally, this index assesses the subjective burden associated with these caregiving

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activities. The Level of Care Index measures perceived strain directly related to caregiving activities. In addition, the caregivers completed a common measure of subjective burden, referred to as The Zarit Burden Interview (Zarit, Reever, & Bach-Peterson, 1980). The ZBI is a 22-item measure of subjective caregiver burden which has been widely used in caregiving research. Of note, the ZBI includes several factors theoretically linked to burnout such as financial burden, feelings of control, emotional well-being, and social/family life.

Burnout: Participants completed two common measures of burnout: The Copenhagen Burnout Inventory (Appendix C; Kristensen et al., 2005) and the Oldenburg Burnout Inventory (Appendix D; Demerouti et al., 2010).

The Copenhagen Burnout Inventory is a 19-item scale which divides burnout into the three subcategories of personal, work-related, and client-related burnout. The CBI has been found to have strong internal consistency ($\alpha = .85$-$.87$). This measure was first used in a large-scale longitudinal study of burnout in the Danish population known as the PUMA study (a Danish acronym for Project on Burnout, Motivation, and Job Satisfaction; Borritz et al., 2006; Kristensen et al., 2005). While the most widely used measure of burnout is the Maslach Burnout Inventory (MBI; Christina Maslach et al., 1986), the CBI was developed with the intent of creating a free, "truly generic" measure of occupational burnout focused on assessing only fatigue and exhaustion. Review of these considerations and details on the construction and validation of the CBI were discussed at length by Kristensen et al. (2005).

The Oldenburg Burnout Inventory (OLBI) is a publicly-accessible 16-item questionnaire which includes subscales for exhaustion and disengagement (Demerouti et al., 2010). Subscales of the OLBI have adequate convergent validity with the MBI ($r = |.37| - |.62|$) as well as good

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internal validity (α = .63 - .79). The OLBI was chosen as the second metric of burnout to evaluate convergent validity since it represents a different conceptualization of burnout theory, specifically highlighting the factor of disengagement.

Depression: Depression was measured utilizing the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977), a widely accepted metric of depression capable of assessing depression from a diverse population both in age and racial/ethnic background (Lewinsohn, Seeley, Roberts, & Allen, 1997). The CES-D has been shown to have good reliability (α = .82), sensitivity (76%), and specificity (77%) at detecting depression.

Social Desirability: Possible bias associated with social desirability was assessed using the SDS-17 (Appendix E). This scale was developed by a group of German researchers in an effort to create a modern measure of social desirability (Stöber, 2001). The SDS-17 has been shown to be valid across multiple settings within US samples, has good internal consistency (α = [0.64 – 0.92]) and strong convergent validity with previous gold-standard measures of social desirability (r > [0.70 – 0.91]). Most importantly, the SDS-17 adequately differentiates between participants attempting to "fake good" versus being honest or "faking bad" (Blake, Valdiserri, Neuendorf, & Nemeth, 2006; Tatman & Kreamer, 2014).

<div align="center">Proposed Research</div>

Using a finalized version of the ICBI, data collected from the full sample of informal caregivers was used to evaluate the hypothesized moderating role of burnout in the relationship between caregiver burden and undesirable caregiving outcomes. The following hypotheses were tested:

Psychometric Exploratory Hypotheses

H1.1: Confirmatory factor analysis will reveal that the ICBI will be a good fit to a unidimensional model compared to a multidimensional model (physical, emotional, interpersonal exhaustion).

H1.2: The average test information function score of the ICBI will account for a greater amount of burnout measurement than the CBI and OLBI.

H1.3: Burnout, as measured by the Informal Caregiver Burnout Inventory (ICBI), will be significantly correlated with objective (hours of weekly caregiving, years spent caregiving, and IADL and ADL dependency) and subjective (Zarit Burden Inventory) caregiver burden.

H1.4: The ICBI will show strong convergent validity (T-test followed by Bland-Altman Plot) with other common metrics of burnout (The Copenhagen Burnout Inventory and the Oldenburg Burnout Inventory).

Auxiliary Hypotheses

H2.1a: Burnout will significantly moderate the relationships between burden and undesirable caregiving outcomes (depression and consideration of transfer to professional care services), whereby burnout compounds the effect of burden on undesirable caregiving outcomes.

H2.1b: Burnout will significantly mediate the relationship between burden and undesirable caregiving outcomes, whereby burnout will function as an explanatory mechanism in the effect of burden on undesirable caregiving outcomes.

H2.2: The ICBI will be significantly negatively correlated with perceived social and professional support.

Statistical Methods

Descriptive statistics were used to characterize the sample of caregivers. Confirmatory factor analysis was completed using MPlus and R (R Development Core Team, 2010), and fit was assessed based on the root mean square error of approximation (RMSEA < .08) and the comparative fit index (CFI > .90; H1.1). Following inability to appropriately conduct CFA due to item pruning, Exploratory Factor Analysis was conducted within R and SPSS. IRT-related analyses were conducted in R (R Development Core Team, 2010) using the "mirt" package (R. Philip Chalmers, 2012). Item threshold parameters and task information functions were calculated and explored visually. Convergent and divergent validity were assessed using a t-test followed by a Bland-Altman Plot (H1.4). Within the Bland-Altman plot, a maximum allowed difference score at the 95% confidence interval was calculated to visually identify any systematic differences between measures. The hypothesis that ICBI will significantly moderate the relationships between burden and undesirable caregiving outcomes (H2.1a-b) was assessed using PROCESS (Hayes, 2017), an SPSS package which allows analysis modeling of logistic regression path analysis. For the purpose of the proposed study PROCESS was used to generate a moderation analysis (Conceptual Model #1; Hayes, 2017) to evaluate the impact of burnout on the relationship between burden and undesirable caregiving outcomes. Finally, association with perceives support (H2.2) were assessed using correlational analyses.

CHAPTER 3: RESULTS

Study Participants

The present study sampled participants during two distinct stages: initial scale development and scale validation.

Initial Scale Development Sampling

Professional and target-population focused feedback on the initial bank of items were collected. Professionals were categorized as anyone working in healthcare or academia who interacts with the target population or relevant research fields (e.g., health care workers who interact with dementia patients and their caregivers, researchers in the field of caregiving, geropsycholgists, and social workers). Target-population feedback was elicited from past or present caregivers of individuals with dementia. These two groups were recruited via word-of-mouth and online forums. A total sample of 20 caregivers and 9 related professionals was collected. Due to feedback from participants a third category was created for those who fit into both caregiver and relevant professional groups. Three individuals identified within this "both" category, however the number may be higher due to this choice not being available until half-way through data collection.

Main Survey Validation Sampling

During the large-scale data collection portion of the study participants were collected via the Amazon MTurk service. To ensure valid response profiles a 3-item screener survey (Appendix D) was used to assess eligibility. Only participants who selected "Alzheimer's or

Dementia-related problems" as the primary diagnosis of their care recipient were funneled into

the main survey. A total of 326 caregivers were included in the final sample. Due to a funneling

issue within the Qualtrics survey 149 of these caregivers did not complete the demographics

portion of the survey. Based on attempt data 3,895 individuals attempted to access the survey

and either: discontinued at the consent screen, were not deemed eligible to participate, or were

funneled out due to invalid responses to validity questions (e.g., "How many hours are there in a

day?"). Full demographic data reported in Table 1.

Caregiver Characteristics

Participants were asked a series of questions regarding their caregiving circumstances.

This included information such as their relationship to the care recipient, the type and amount of

care they provide, and caregiver burden information. Full caregiving circumstances information

is detailed in Table 2. In concordance with previous research, the population varied widely on

both demographic and circumstantial factors, therefore the profile of an "average" caregiver is

difficult to capture. In this study, the average caregiver was a 36-year-old, married female who is

employed full-time and holds at least a bachelor's degree. This "average" caregiver shares

caregiving responsibilities equally with at least one other individual, provides 36 hours of care

per week, and lives with the care recipient.

<u>Scale Construction</u>

Item-by-item feedback from both in-field experts and caregivers were generally positive,

however several qualitative suggestions were given. Item appropriateness ratings ranged from

8.10 to 9.76, while item clarity ranged from 8.59 to 9.87. Despite high ratings, qualitative

feedback on items were considered and several questions were modified to improve face validity

and theoretical fit to the construct of burnout. As no items stood out as inappropriate or unclear,

no items were pruned during this stage. Once the sampling from the full online survey was

complete polychoric correlations were examined to identify poor fit items ($r < .30$). Item-total

correlations ranged from 0.61 to 0.76, therefore no further items were removed. Further, internal

consistency was good at this point (Cronbach $\alpha = .90$).

IRT Analysis was conducted prior to validity and reliability analyses. Individual items

were assessed using several indicators of psychometric strength (e.g., item trace lines, item

information curves, coefficient alpha, and goodness of fit indices). Items were pruned based on

low coefficient alpha scores, poor fit (Table 3), poor item information (Figure 1), and poor item

trace profiles (Figure 2). Based on these criteria, and unique contributions of items to the breadth

of burnout captured by the scale, 15 items were removed from the scale. The final 10-item scale

consisted of items 6, 10, 11, 12, 14, 15, 16, 17, 18, and 20 (Figure 3). Internal consistency for

this 10-item version was excellent (Cronbach $\alpha = .92$).

Scale Validation

Convergent validity was examined between the ICBI and two gold-standard measures of

occupational burnout, the CBI and OLBI. As expected, there were strong positive correlations

between the ICBI-10 and OLBI ($r = .66$, $p < .001$) and CBI ($r = .84$, $p < .001$). As the CBI is

intended to be interpreted by each of the three individual subscales, analyses included the CBI

subscales of Personal, Work-related, and Client-related burnout (Kristensen et al., 2005). The

ICBI has similarly strong positive correlations with Personal ($r = .82$, $p < .001$), Work ($r = .79$, p

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<.001), and Client-related ($r = .71$, p <.001) burnout subscales. Convergent validity was confirmed by significant t-tests indicating a high degree of agreement between each subscale (Table 4). Of note, Bland-Altman plots were not necessary given the significant t-tests of scale difference and mean scores. Divergent validity was quantified as the level of agreement between the ICBI and CESD, under the assumption that burnout and depression, while correlated, are theoretically unique constructs. Given a non-significant t-test result for ICBI and CESD difference scores (Table 4), a Bland-Altman plot was constructed (Figure 4). Disagreement between ICBI-10 and CESD is apparent due to several points falling outside of the 95% confidence intervals. Further, proportional bias is illustrated via the clustering of scores increasing as mean score increase, indicating the two scales do not measure the latent variable of burnout or depression equally across a spectrum of observations. To better contrast this difference, a scatterplot was constructed depicting CESD and ICBI scores (Figure 5). While both measures are significantly correlated, they appear to measure unique constructs due to this proportional bias. A follow-up analysis of variance (ANOVA) was conducted to confirm proportional bias, which yielded significant results (F (1, 324) = 34.40, $p < .001$; β = -.31). Given these findings, the ICBI appears to adequately discriminate burnout from depression and shows good divergent validity.

Predictive validity was assessed by comparing the relationships of the ICBI to gold-standard measures of burnout among common correlates of end-stage burnout, such as high burden, depression, and intent to transfer care recipient to a long-term care facility. Further, predictive validity was examined with perceived social support, which is theorized to be inversely related to burnout. The ICBI, CBI subscales, and OLBI were all significantly correlated

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to intent to transfer, Zarit Burden Inventory scores, and CESD scores. Comparative strength of each measure was assessed using a Fisher r-to-z transformation to compare correlation coefficients (Table 5). The ICBI functioned on-par to each measure of burnout with two exceptions. The CBI Client Burnout subscale was more strongly related to intent to transfer to long-term care ($z = -1.97$, $p = .05$), and the OLBI was more strongly related to perceived social support ($z = -3.99$, $p < .001$). Interestingly, the CBI Work Burnout subscale had no significant relationship to perceived social support.

Social desirability bias was examined within the ICBI and gold-standard measures of burnout. Each burnout measure had a significant negative relationship to social desirability. This indicates that as reports of burnout increase, responses indicating social desirability bias decrease. There were no significant differences in the relationships between SDS-17 scores and each measure of burnout (Table 5).

To compare the psychometric properties of the ICBI to other scales of burnout, IRT analysis was used to quantify the average test information function score of each measure (Table 6). Results indicate that the ICBI captures the most area (60.49%) within the 95% bands of burnout, followed by the CBI work-related burnout (56.26%), CBI personal burnout (51.90%), OLBI (46.04%), and CBI client-related burnout (44.57%). To better visualize the difference in test information captured by each scale, the five curves are graphed along the same standard axes in Figure 6.

Theoretically hypothesized relationships between burnout and objective and subjective caregiver burden were examined with the ICBI. Burnout shared a significant positive correlation with weekly hours of caregiving ($r = .12$, $p = .036$), number of IADLs ($r = .24$, $p < .001$) and

ADLs ($r = .31$, $p < .001$) performed, and score on the Zarit Burden Inventory ($r = .59$, $p < .001$; Table 7). Sensitivity and specificity were examined using a Receiver Operating Characteristic (ROC) curve analysis. Caregivers were identified as at high risk of burnout based on "severe" scores of 60 or higher on the ZBI and average hours of care provided per week exceeding 20 hours. Given these parameters 42 out of 326 caregivers were put into the "severe" burden category. Similarly, a "high burden" category was created by identifying caregivers who scored a 40 or higher on the ZBI and provide 20 or more hours of care weekly; these parameters resulted in 143 out of 326 caregivers fitting the "high burden" category. The ICBI showed good capability at detecting severe burden caregivers (AUC = 81.0%), and fair capability at detecting high burden caregivers (AUC = 74.4%). Notably, when compared to other measures of burnout, the ICBI performed similarly (Figure 7). Given ROC estimates, a potential cutoff for "severe" burnout is any score exceeding 32 on the ICBI (sensitivity = 76.2%, specificity = 21.1%). No robust cutoff could be determined for "high" burnout caregivers. The most optimal cutoff would be a total score of 27 or higher (sensitivity = 64.3%, specificity = 30.6%).

Hypothesis 1.1 sought to explore the factor structure of the ICBI with a comparison of two CFA models. However, due to extensive item pruning, the proposed subscale structure was no longer appropriate for CFA. Factor structure was therefore explored using an Exploratory Factor Analysis (EFA). All 10 items of the ICBI-10 measure were subjected to an EFA with oblique rotation (Promax) followed by an EFA with no rotation. The Kaiser-Meyer-Olkin measure verified the sampling adequacy for the analysis, KMO = .913. Bartlett's test of sphericity indicated that correlational structure of the factor analysis is adequate (χ^2 (45) = 1872.17, $p < .001$). An initial Scree Plot (Figure 10) indicated one- or two-factor models.

Promax rotation was used to examine the two-factor model; a Kappa of 4 was used in an attempt

to reduce correlation between the two factors (Hendrickson & White, 1964); however, factors

remained highly correlated despite this correction. Given these results, a single-factor solution

was found to best fit the data. The one-factor model accounted for 56.91% of the variance (Table

8). With no rotation adjustment, all factors were strongly associated with the single factor of

burnout, ranging from 0.678 to 0.821. The one-factor model is depicted in Figure 11.

Burnout as a Mediator or Mediator

It was hypothesized that the well-established relationship between caregiver burden and

undesirable caregiving outcomes of depression and transfer to long-term care services is

moderated by burnout (Figure 8). Hypothesis 2.1a was examined using SPSS PROCESS model

1, which explores a simple moderation. Variables were mean-centered to facilitate meaningful

interpretation of the resulting regression parameters. In the overall model, caregiver burden and

burnout were significant predictors of depression (F (3, 322) = 78.37, $p < .001$, $R^2 = .42$). As

caregivers reported higher levels of burden their report of depression symptoms similarly

increased ($b = 0.33$, t (322) = 9.04, $p < .001$). Similarly, as caregivers reported higher levels of

burnout, they reported increased depressive symptomatology ($b = 0.27$, t (322) =3.85, $p<.001$).

Figure 9 shows the interaction between caregiver burden and burnout scores ($b = -0.08$, t (322) =

-3.03, $p = .003$). The interaction remained significant at all levels. For caregivers reporting low

levels of burden, burnout had the strongest impact on depression scores ($b = 0.40$, t (322) = 9.29,

$p < .001$). This effect remained significant, but slightly weaker, at average levels of burden ($b =$

0.33, $t(322) = 9.04$, $p < .001$), and significant but faintest at high levels of burden ($b = 0.25$,

$t(322) = 5.63$, $p < .001$). Further exploration of this moderation was made difficult due to a significantly reduced sample size ($n = 172$) when excluding caregivers who did not report level of education or relationship status. However, analysis was conducted controlling for these factors and for high-burden caregiving status. High-burden status had no impact and the moderation remained significant, however controlling for both education and relationship status resulted in a non-significant moderation ($t(170) = -.44$, $p = .66$). Finally, the hypothesizes moderation of burden and intent to transfer to long-term care services was also explored. Results indicate that burnout does not significantly moderate the relationship between caregiver burden and intent to transfer ($t(245) = 1.20$, $p = 0.23$).

Hypothesis 2.1b sought to explore a simple mediation of the relationship between caregiver burden and outcomes of depression and intent to transfer (Figure 8). Mediation analysis was first conducted examining depression as an outcome using SPSS PROCESS model 4. Results indicated that caregiver burden significantly predicted depressive symptoms (the *c* pathway), reported in Table 9. Caregiver burden was then used to predict a mediator variable of burnout (the *a* pathway), results indicate that burnout was positively related to burden ($t(324) = 13.21$, $p < .001$). Next, the relationship between the mediator, burnout, and depression was analyzed while controlling for burden (the *b* pathway). Burnout was positively related to depressive symptoms ($t(323) = 9.02$, $p < .001$). Finally, the mediated relationship of burden and depressive symptoms was examined when the mediator was added to the model (the *c'* pathway). Partial mediation was found, indicating that the relationship between burden and depression remained significant while controlling for burnout ($t(323) = 4.16$, $p < .001$). The total indirect effect size was calculated with the index of mediation, resulting in a total effect size of $ab_{cs} =$

0.13, accounting for 39.5% of the total effect. Mediation analysis was also conducted to explore the relationship between burden and intent to transfer to long-term care services. Results indicated no significant mediation effect of burnout on the relationship between burden and intent to transfer.

CHAPTER 4: DISCUSSION

This study sought to build, validate, and compare a novel measure of burnout developed for informal caregivers of individuals with dementia. Overall, the ICBI-10 was found to be a highly reliable, valid, and brief instrument that performs on-level with gold-standard measures of occupational burnout. During the scale development stage expert-feedback was used to refine a 25-item bank of questions, no items were found to be inappropriate or so poorly worded they needed to be removed. Items were further scrutinized using IRT analysis once the full sample of current-caregivers was collected. During this phase 15 items were identified as weak contributors to the overall scale, poorly structured, or redundant, therefore these items were pruned resulting in a final 10-item version of the ICBI. Analysis of factor structure indicated a one-factor model best fit the data. IRT analysis showed the ICBI-10 to have high test-information with breadth to capture burnout along the spectrum of severity. Further, ROC analysis revealed a possible "severe burnout" identifier for those who obtain a score of 32 or higher on the instrument. Finally, auxiliary analyses explored the hypothesized mediated or moderated relationship of burnout on the relationship between burden and undesirable caregiving outcomes. Burnout was found to significantly moderate the relationship between burden and depressive symptoms; this relationship was strongest at lower levels of burden potentially revealing a low-burden high-burnout subgroup of caregivers who experience increased depressive symptoms. This is the first line of research exploring the validation of a burnout measure within informal caregivers, therefore further replication, test-retest, multicultural validation, and exploration of burnout within this population is needed. Taken as a whole, these findings indicate that the ICBI-10 is a

powerful yet brief measure of burnout with potential to be used within clinical and academic settings.

Hypothesis 1.1 was restructured as an EFA to better accommodate the final pruned version of the ICBI which had no clear sub-scales. A one-factor model was found to be the best fit. This one-factor model accounted for a large portion of the variance and all items had moderately high to high component scores. Initial analysis examined the possibility of a two-factor model, but high levels of multicollinearity could not be compensated for without excessive artificial corrections (i.e., setting Promax rotation Kappa to one). These findings lead to the conclusions that burnout captured in the ICBI-10 is best characterized based on a single factor. This single-factor model is ideal in that H1.1 sought to confirm a unidimensional model that represented a burnout from the view of exhaustion. Further, as shown by Hinkin (1995) a deductive approach was taken to construct the original bank of items, with the intent of capturing burnout as a unidimensional phenomenon. Given that a one-factor solution was found to best fit the ICBI-10, the original intent of creating a scale exclusively focused on exhaustion was achieved.

Results supported hypothesis 1.2, where the ICBI-10 had a greater average test information function score compared to both the OLBI and CBI subscales, indicating the ICBI-10 captured a greater depth of the latent variable of burnout. With respect to hypothesis 1.3, the ICBI-10 was found to have weak to moderately strong correlations with various measures of objective and subjective burden. Further, the ICBI-10 had significant relationships with correlates of severe burnout such as depression and intent to transfer to long-term care services. Using and IRC curve, the ICBI-10 showed good capability of detecting caregivers experiencing

severe burnout (ICBI Score > 32). Finally, hypothesis 1.4 was supported by results indicating the ICBI-10 had strong convergent validity with other measures of burnout and was able to adequately distinguish burnout from depression.

Given support for psychometric hypotheses, a series of auxiliary hypotheses were explored. First, in H2.1a, burnout was examined as a moderator of the relationship between burden and undesirable caregiving outcomes whereby burnout compounds the effect of burden on such outcomes. Analysis supported the moderating effect of burnout on the relationship between burden and depression, in which burnout compounds the effects of burden on depressive symptoms. Of interest, burnout had the strongest impact on this relationship while at lower levels of burden. These results indicate that measurement of burnout may supplement caregiver assessments by enhancing detection of undesirable caregiving outcomes despite low burden levels. Additional analysis included re-running this moderation analysis while controlling for caregiver relationship status, level of education, and categorization into a high-burden group. The moderation was insignificant when accounting for these control variables. Importantly, to control for these variables, the sample size was reduced to 170 participants, which is significantly lower than the sample size suggested by earlier power analyses. It is unclear if a larger sample would have led to significant results, therefore future studies attempting to examine this relationship are encouraged to obtain an appropriate sample size and other control variables such as SES. Future research should evaluate this noteworthy yet incomplete finding. Similarly, family composition and caregiving relationships remain an important aspect of caregiving circumstances, however due to highly variable and missing responses, accounting for these variables was beyond the scope of this project.

A novel result of these moderation analyses was the interaction effect of ICBI burnout on the relationship between the ZBI burden and depression scores. One possible interpretation of this finding is a ceiling effect in which caregivers reporting extremely high levels of burden will report similarly elevated levels of burnout, while caregivers reporting lower levels of burden are more variable in their report of burnout. This is to say, at high levels both burden and burnout, which are independently and strongly associated with depression, caregiver reports of depression will converge. On the other hand, at low levels of burden, the impact of burnout becomes more pronounced as depression scores are less-influenced by burden. This is to say, while caregiving burden was found to be significantly related to burnout, this study also found that high levels of burnout were possible independent of known correlates such as burden, social support, and depression. These findings indicate the existence of a sub-group of individuals who experience high burnout but report low levels of burden. This subgroup may be uniquely at risk of being overlooked in caregiving research and implies the need for new perspectives on caregiving support interventions to address unidentified factors contributing to burnout in low-burden caregivers. Importantly, the temporality of this relationship could not be established in the present study. It is possible this sub-group of low-burden high-burnout caregivers reporting increased depressive symptoms contain individuals who experienced elevated depressive symptomology prior to taking on the role of caregiver. Previous studies have examined the relationship of prior depression and depression while caregiving (Neundorfer, McClendon, Smyth, Strauss, & McCallum, 2006) as well as longitudinal correlates of increased depressive symptoms while caregiving (Smith, Williamson, Miller, & Schulz, 2011). These studies may serve as models to integrate burnout within similar research endeavors.

The impact of burnout on the relationship between burden and intent to transfer to long-term care services was also assessed, however burnout did not significantly contribute to this relationship. This may be explained by the already strong association between burden factors (e.g., number of ADLs and IADLs assisted with, cost of care, and disease severity) and consideration to transfer an individual to long-term care services. Importantly, intent to transfer represents an attempt at assessing for premature transfer to long-term care services. Premature transfer remains a difficult and extremely complex variable to capture in caregiving research. The complicated nature of this variable may also account for the high variability in response and remains an important subject for future research to address. Currently, there is no succinct definition of premature transfer to long-term care services or criteria by which one can judge if this were to occur. Many non-burden related factors may also contribute to this decision (culture, attachment, financial standing, and care recipient wishes, and caregiver health). In the present study, the wording of intent to transfer was limited to transfer to long-term care services. Future attempts to capture this variable may consider questions addressing caregiver intent to remain a caregiver (i.e., allow others to assume caregiving responsibilities) as this may be a better indicator or end-stage burnout, especially in cases where caregivers are restricted in their ability to seek long-term care services or have other factors influencing their ability to make such decisions.

Finally, Hypothesis 2.2 explored the relationship between perceived social support and burnout. Analysis revealed a significant negative correlation between burnout and perceived social support. Interestingly, burnout as measured by the OLBI was significantly more strongly related to perceived social support compared to burnout measured by the ICBI-10. This

difference may be accounted for by the conceptualization of burnout in each measure. The OLBI contains two subscales which account for burnout: disengagement and exhaustion, whereas the ICBI-10 attempts to capture burnout exclusive to exhaustion. Each scale does an adequate job at quantifying burnout; however, this finding highlights the impact of different conceptualizations of burnout as a latent variable. The impact of social support is well-established within caregiving research and is thus a common target of interventions. This finding extends this known impact to burnout and further solidified the importance of social support in reducing caregiving burden as well as exhaustion.

Limitations

This study has four major limitations: sample size, sample demographics, cross-sectional design, and a need for replication. The collected sample size provided adequate power for the core analysis, however a coding-error within the digital survey funneling led to a portion of participants not being presented with certain demographic questions, reducing some analyses to $n = 170$. This limitation inhibited analyses attempting to control for demographic variables. Similarly, since demographics for a significant portion of the sample cannot be adequately assessed, it is possible our sample is different from a typical sample of caregivers. This issue is compounded by the online nature of the study. Caregivers tend to be married (61%) Caucasian (61%) females (60%) who care for one recipient (82%), usually a relative (85%), are on average 49 years old, (National Alliance for Caregiving (NAC) and AARP Public Policy Institute, 2015). However, in this sample caregivers were much younger ($M = 35.74$), racially/ethnically diverse, and less often married (33.9%). Of note, the sample did not appear to differ in other demographic

categories. In a similar vein, this study recruited only US residents who speak English; therefore, generalization of these results to non-English speaking populations cannot be determined based on these results. Of particular note, caregiving dynamics and expectations vary by culture and merely translating an instrument into another language may not be adequate to measure caregiving burnout in, for instance, Spanish speaking populations, in an equivalent fashion. Nonetheless, future research may examine these measurement invariance between translated versions of this and other burnout measures between cultural populations.

A particularly limiting factor of this study is the cross-sectional nature of data collection. Cross-sectional designs carry several limitations, predominantly in the interpretation of statistical analyses which speak to causal relationships. Though the primary analyses of this study are unaffected by this limitation, causality or temporality of relationships captured cannot be clearly established. Notably, this is a limiting factor for the auxiliary analyses which included mediation and moderation analyses. As is discussed by Winer and colleagues (2016), causality captured by mediation and moderation analyses speak to a process unfolding over time, which requires longitudinal data. Given that this study does not utilize longitudinal data, causality or temporality cannot be established, meaning the relationship between burden, depression, and burnout could interact in a variety of directions. Therefore, while a relationship between these factors has been identified, further research is required to understand the way in which they interact. In additional to limitations associated with lack of control variables, these findings should be interpreted only as preliminary and requiring replication with a more robust dataset.

A final limitation to this study is the necessity to replicate findings within a new sample of caregivers. This is for two reasons. Firstly, the sample used to prune items with IRT analysis

and was the same population later used for analysis of auxiliary hypotheses. Given this sampling

overlap, the auxiliary hypotheses should be taken with a caveat as potentially self-fulfilling or

over/under-fitted compared to what future findings may reveal. Thirdly, this study was unable to

examine test-retest reliability of the ICBI-10 due to methodological limitations. Caregiver

support interventions is a prime setting for the use of the ICBI-10, therefore establishing a test-

retest reliability prior to using the ICBI-10 within a longitudinal study is essential. Along these

lines, general replication of this study, as well as application to more diverse populations, new

sub-groups of informal caregivers, and in different clinical and research settings are all

reasonable next steps in the implementation of the ICBI-10.

<p style="text-align:center">Implications</p>

Burnout remains a construct which can be widely applied to demanding, low-support,

low-control occupational or life roles. The present study did not identify a new form of burnout.

Instead, it validated the existence of burnout within dementia caregivers and demonstrated the

use of a novel tool in the quantification of burnout within this area. The strength of this study lies

in the confirmation of our approach to measure burnout in a novel population with existent and

new tools. Although often overlooked, a central role of science is to develop and validate

accurate tools to measure a construct of interest. Just as it would be ill-advised to trust the

reading of an oral thermometer used on of a pot of boiling water, it would similarly be ill-advised

to use an occupational measure of burnout within familial dementia caregivers without first

ensuring measurement accuracy. As one natural phenomenon requires different measurement

methods dependent on setting, so too must we respect the need to validate the tools we use to

<p style="text-align:center">42</p>

quantify psychological phenomena in distinct populations. Caregiver burnout may not be an exclusive form of burnout, but the onset, course, and impacts of caregiver burnout may be uniquely informed by the experience and diversity of individuals in this role.

This study lays the foundation for several lines of future research. While this study represents an initial foray into capturing burnout experienced by informal caregivers, much work needs to be done to ensure the ICBI-10 can adequately measure burnout within this diverse population. It is well-established that caregivers are an extremely heterogeneous group, therefore efforts to generalize this scale should include targeting specific sub-populations such as: high-burden caregivers, spousal caregivers, those in the "sandwich generation," caregivers to newly-diagnosed individuals, caregivers with varied access to resources (social, financial, support services), caregivers from different cultural backgrounds, and informal caregivers of conditions other than dementia. While the ICBI-10 performed well with gold-standard measures of occupational burnout, which have been used with a wide-variety of populations, it is unclear how well the ICBI-10, or any measure of burnout, will capture exhaustion within these different groups. Of note, the CBI and OLBI both performed well therefore, this study also represents an initial validation of the use of these scales within the informal caregiver population. While the ICBI-10 was created specifically for informal caregivers, and is shorter than the CBI and OLBI, each measure appears to capture burnout adequately. These findings strengthen any previous or future research conducted using these measures of burnout within dementia caregivers.

The topic of burnout has made its way into the zeitgeist of the last several decades. It has been widely studied in occupational settings, and recently extended to other areas of life. However, this important indicator of exhaustion, fatigue, and potential for quitting or "burning

out" has been left widely unaddressed within the informal caregiver population. Prior to this study, burnout could only be measured by adapting occupational measures of burnout. This method has several methodological and psychometric limitations. For these reasons, the ICBI-10 was constructed as a brief yet effective measure of burnout within informal caregivers of individuals with dementia. In this study the ICBI-10 performed on-level with two gold-standard measures of occupational burnout and was found to be related to subjective and objective caregiver burden, social support, intent to transfer, and depressive symptoms. As these variables are often the focus of caregiver interventions (Gaugler, Yu, et al., 2009; Pinquart & Sörensen, 2006; Schulz & Martire, 2004), the ICBI may improve assessment for any researcher or healthcare professional interacting with informal caregivers. Finally, this study contains the first documented use of a caregiver burnout scale, which explores the theorized moderating role of burnout in the relationship between burden, depression, and long-term care transfer. Results from this study provide a foundation for stronger and more theoretically sound burnout research within the field of informal caregiving. While the need for further norming and replication of this study remain, the ICBI-10 stands as the first psychometrically validated measure of burnout for informal caregivers. Hopefully, the adoption of the ICBI-10 into caregiving research and clinical settings will offer a new perspective into the experience of caregivers and enhance detection of undesirable outcomes for caregivers and those they care for.

APPENDIX A: FIGURES
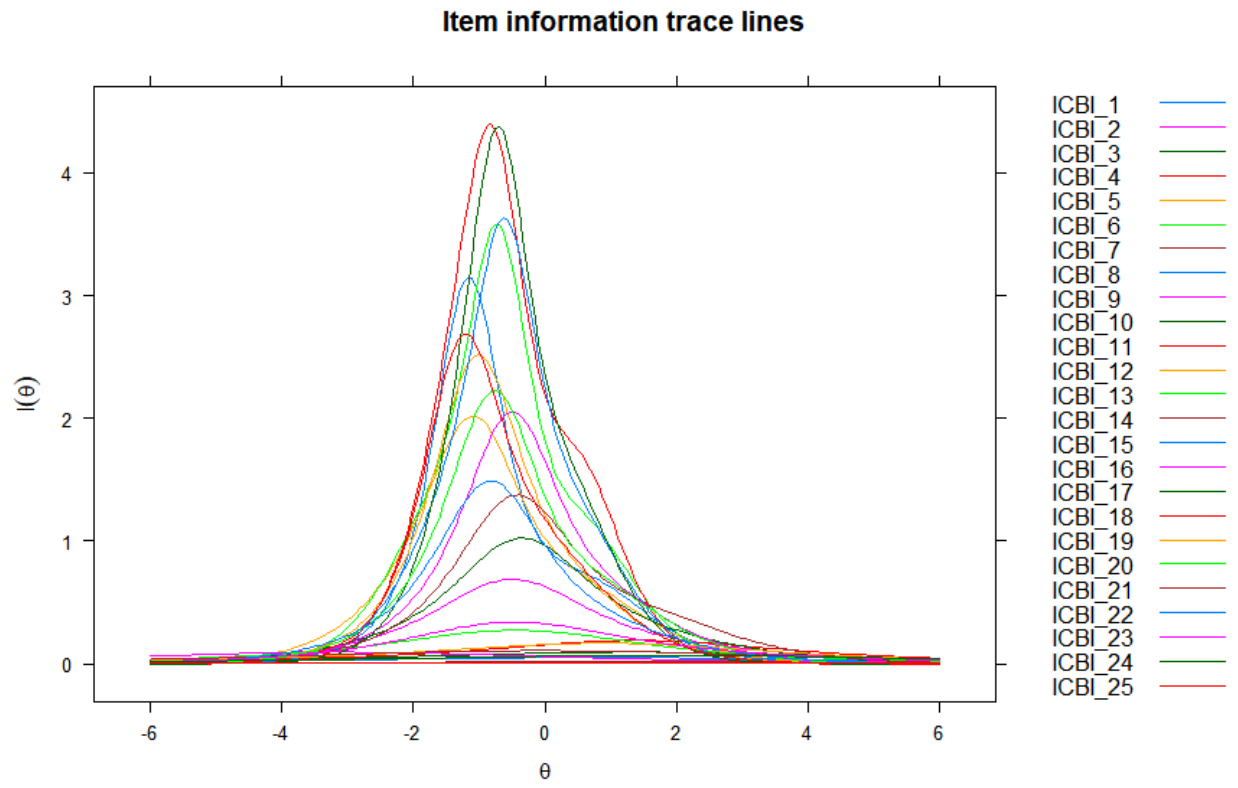
Figure 1: Combined Item Information Trace Lines for ICBI-25 Items
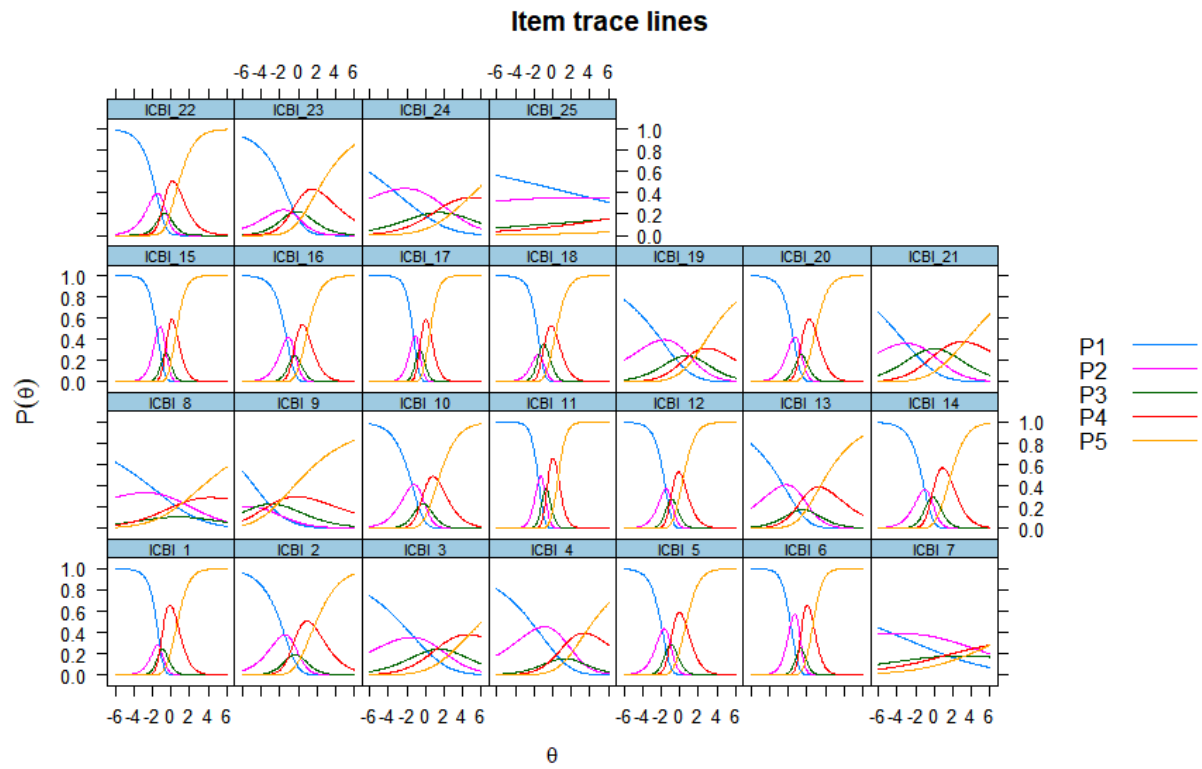
Figure 2: Item Trace Lines for Individual ICBI-25 Items

Informal Caregiver Burden Inventory – 10 Item Form

1. I feel burned out from caregiving.

2. I do not have the time or energy to take care of myself.

3. I feel physically drained.

4. Caregiving is physically exhausting.

5. I often feel unwell.

6. I feel tired all the time.

7. I am irritable.

8. I feel emotionally drained.

9. Caregiving is emotionally exhausting.

10. I am often frustrated.

Original items renumbered and listed in order: 6, 10-12, 14-18, 20

Figure 3: Items Retained in Informal Caregiver Burnout Inventory-10
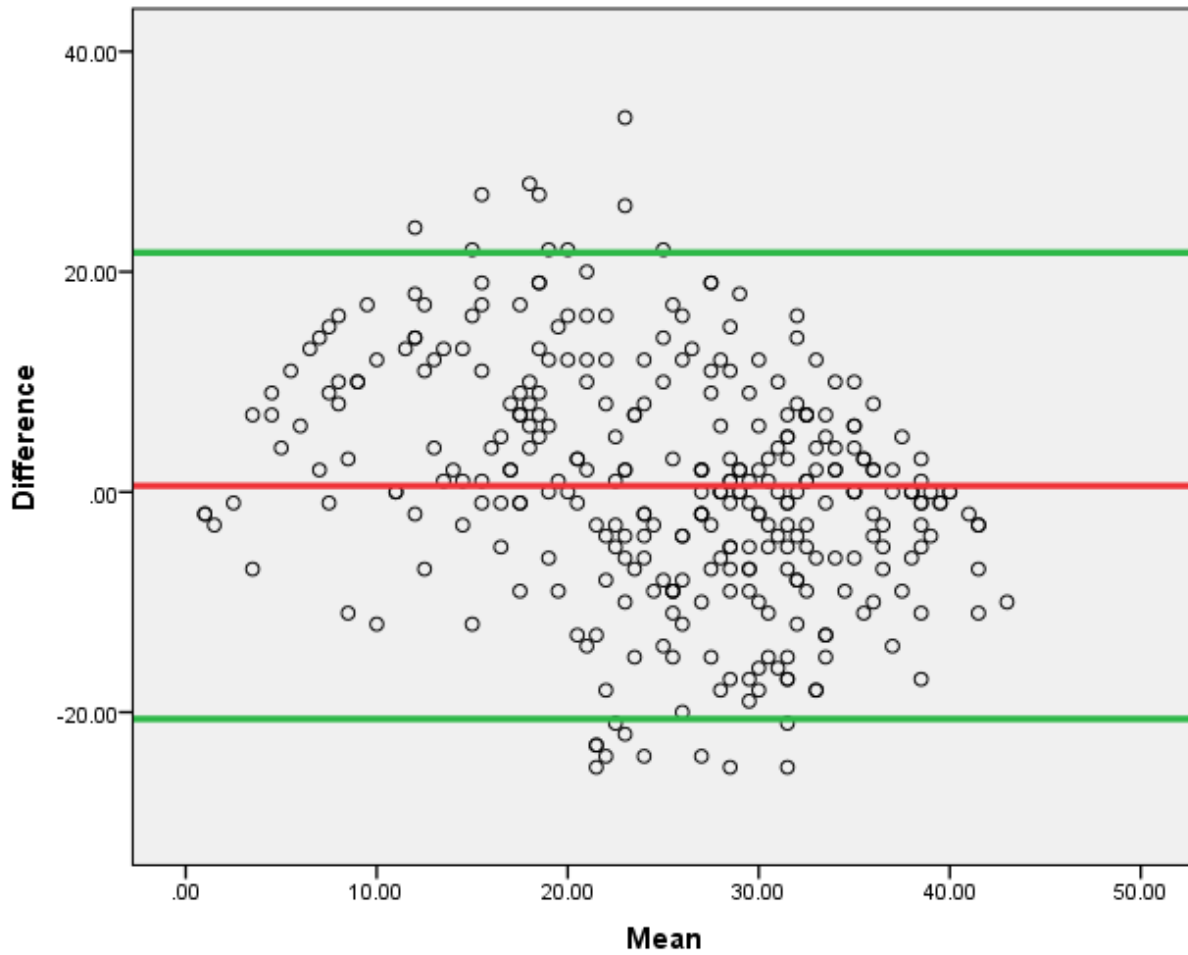
Figure 4: Bland-Altman Plot for ICBI and CESD Difference and Mean Scores.

Green lines indicate 95% confidence interval cutoffs. Scores falling outside of this line indicate disagreement between scales. Red line indicates mean difference score.
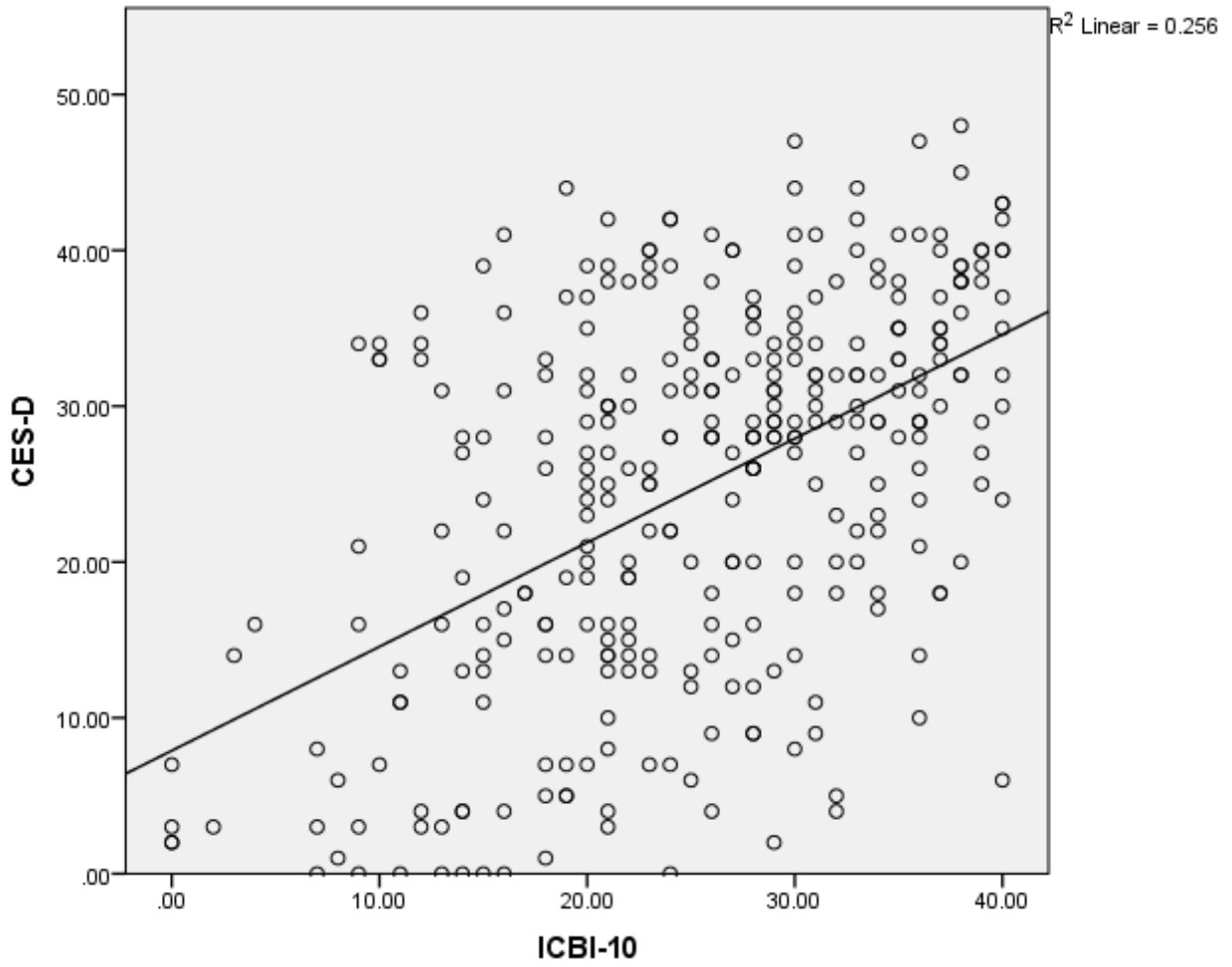
Figure 5: Scatter Plot of CES-D and ICBI-10 Total Scores
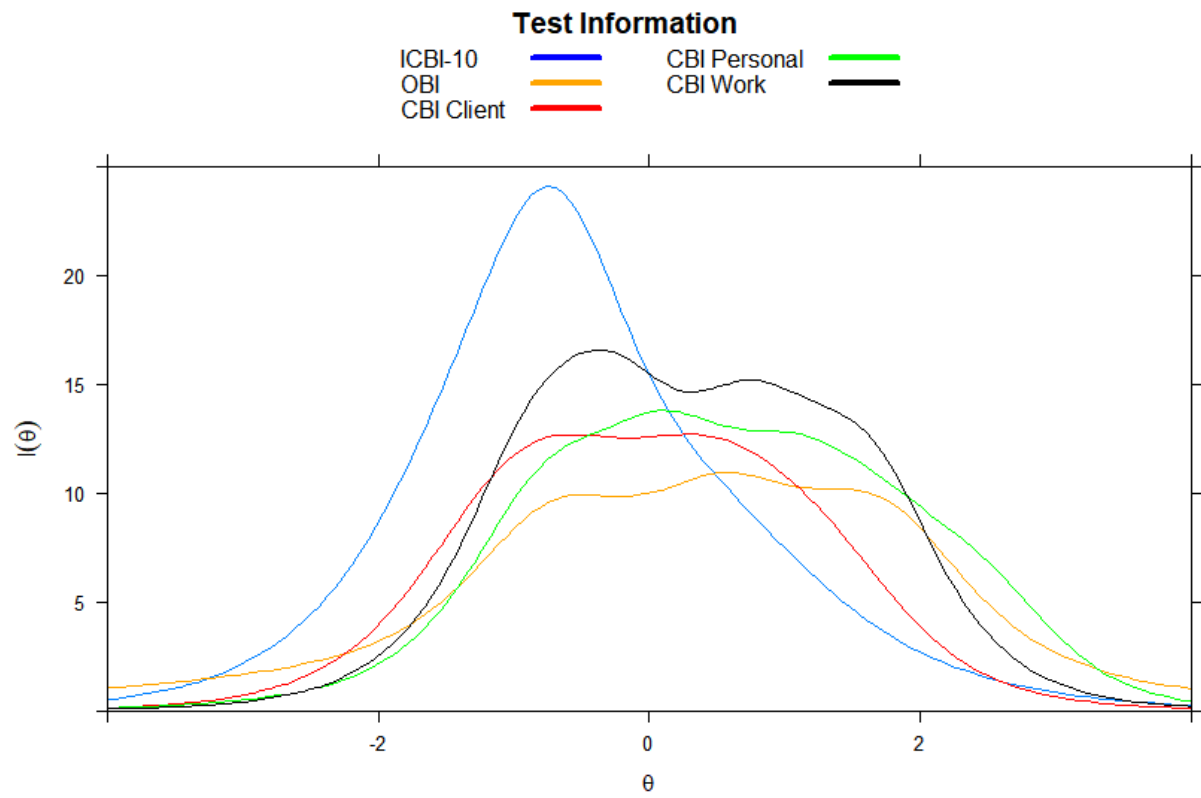
Figure 6: Test Information Curves for Burnout Measure
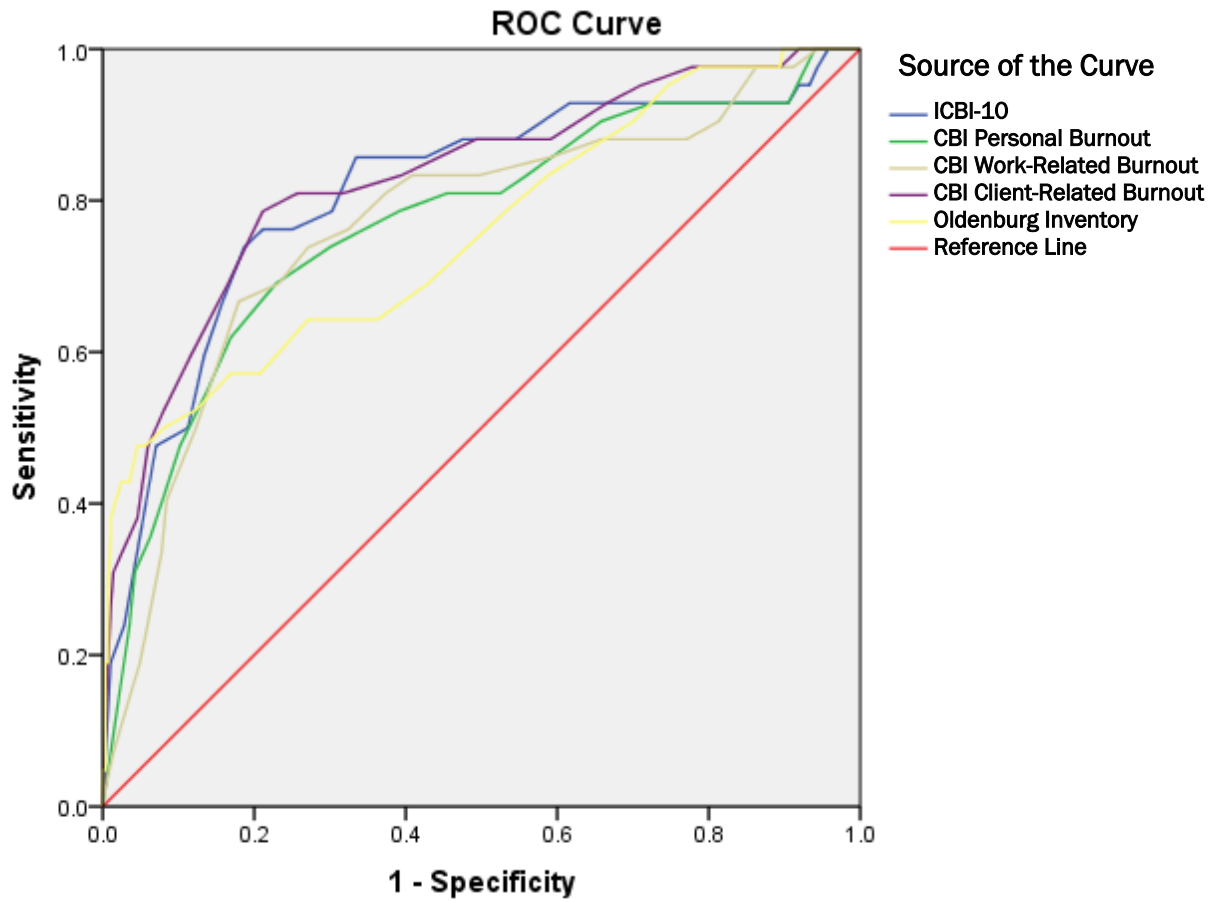
Figure 7: ROC Curve Measures of Burnout and Severe Burden Caregivers

Note: Severe burden caregivers defined as those providing 20+ hours of care per week and scored a 60+ on the Zarit Burden Inventory, the recommended "severe" burden cutoff (Stagg & Larner, 2015).
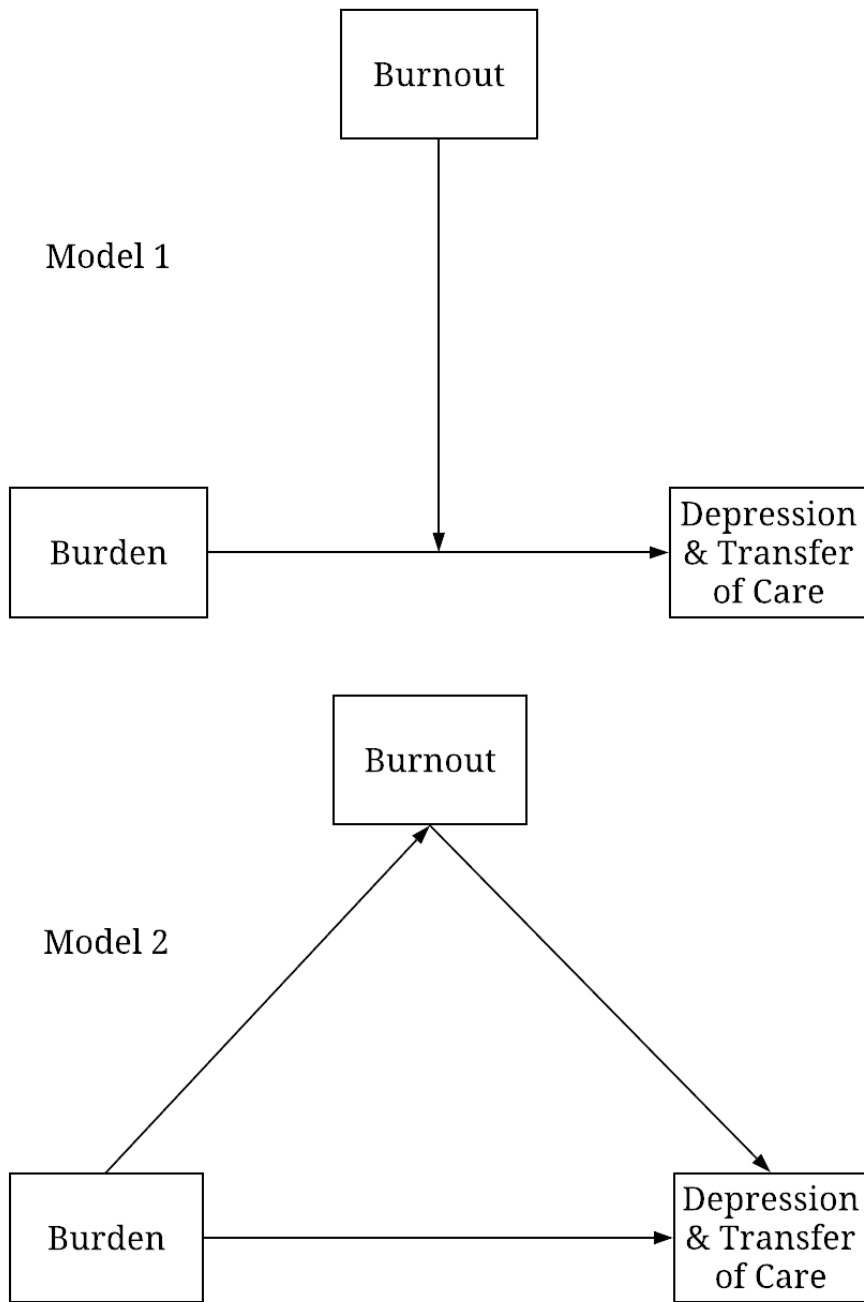
Figure 8: Theorized Moderation and Mediation Models
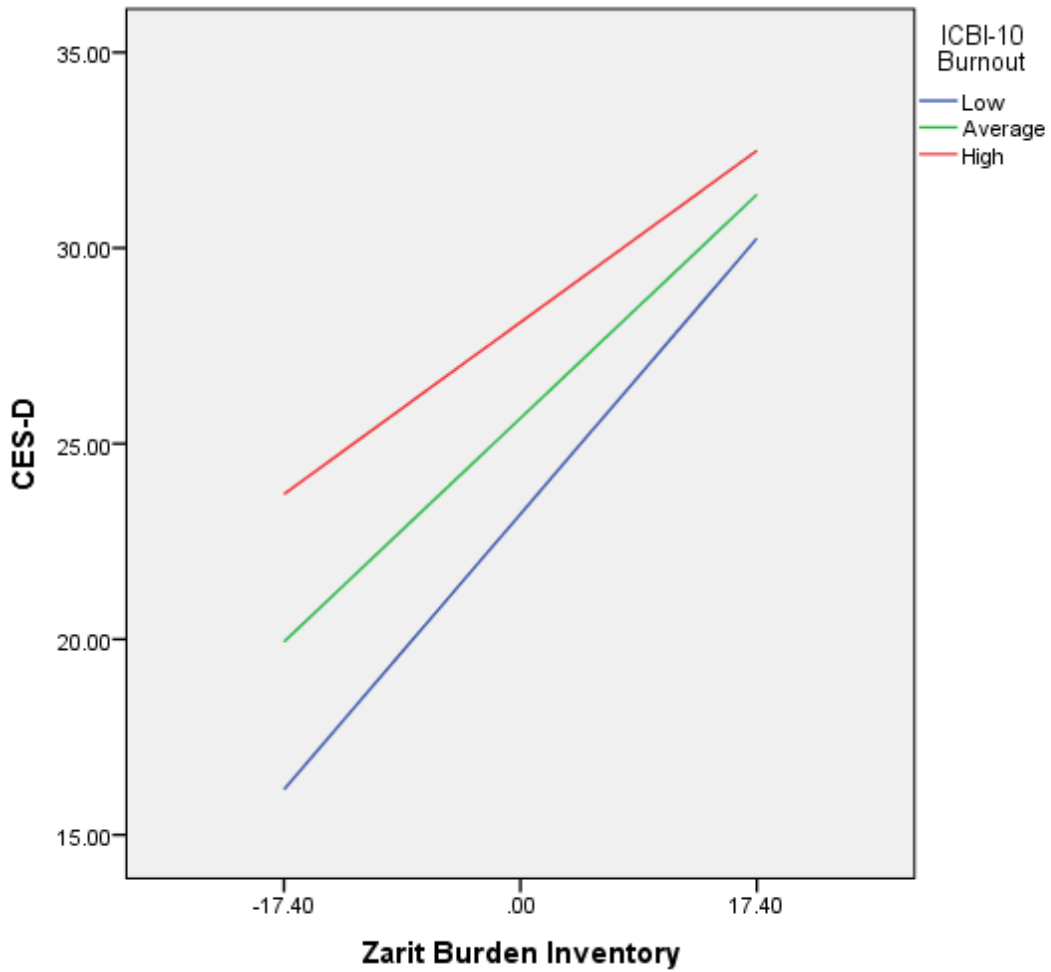
Figure 9: Interaction of Caregiver Burden and Burnout on Depression

Note: Burnout plotted lines represented at 3 levels: -1 SD, mean score of 0, and +1 SD.
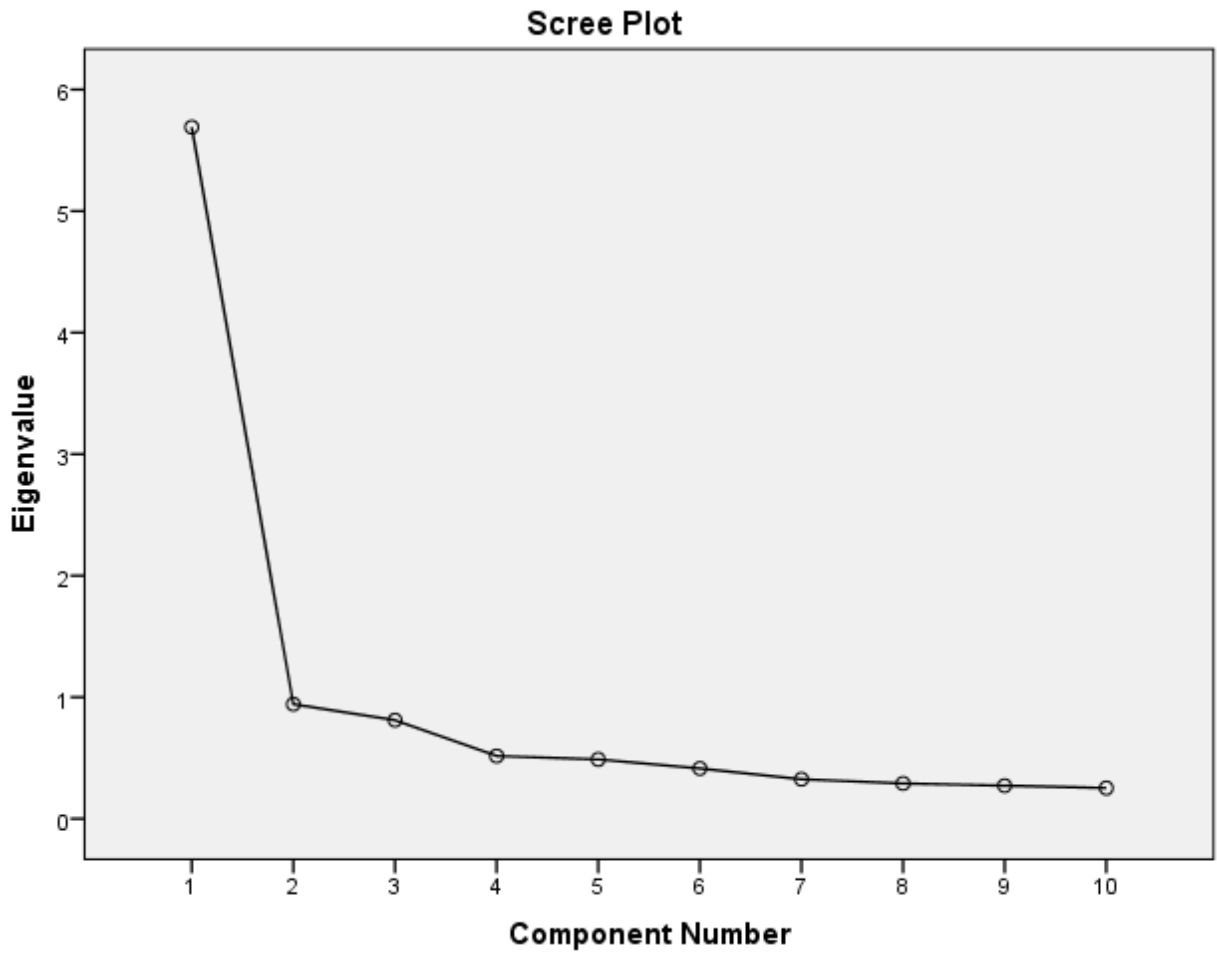
Figure 10: Scree Plot for ICBI-10 Factors
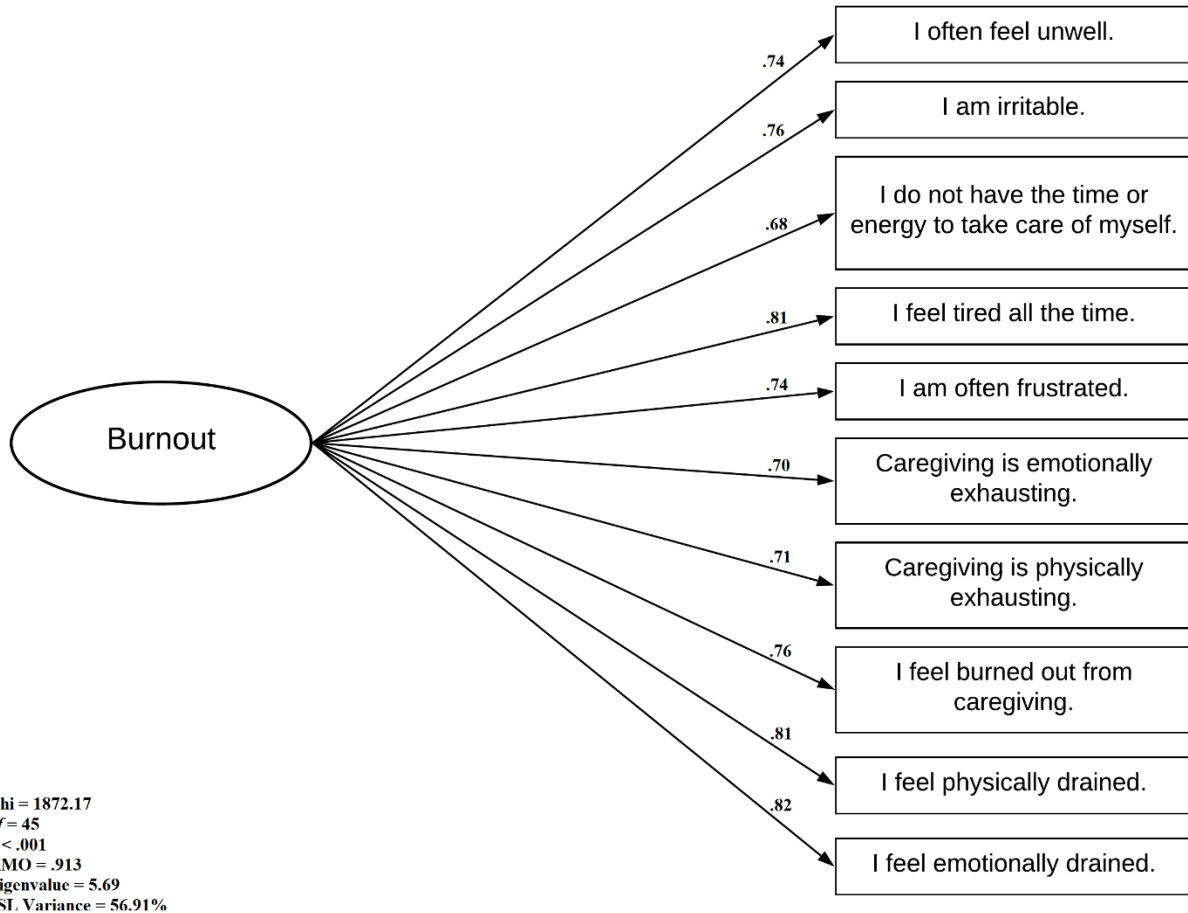
Figure 11: One-factor Model of ICBI-10

Notes: SSL = Sum of Squared Loadings, KMO = Kaiser-Meyer-Olkin Measure of Sampling Adequacy

APPENDIX B: TABLES

Table 1: Sociodemographic Characteristics of Participants

	M	*SD*
Age [a]	35.74	13.00
Biological Sex [b]	*n*	*%*
Male	63	42.06
Female	114	57.94
Member of LGBTQ Community [b]		
Identifies as LGBTQ	28	15.82
Does not identify as LGBTQ	149	84.18
Race/ethnicity [b]		
White or Caucasian	139	78.53
Black or African American	20	11.30
Hispanic/Latino(a)	13	7.34
Asian / Pacific Islander	13	7.34
Native American	4	2.26
Other / Prefer not to answer	4	2.26
Marital Status [b]		
Married	60	33.90
Divorced/Separated	14	7.91
Widowed	5	2.82
Living with a partnered	20	11.30
Single, never married	59	33.33
With a partner, not living together	19	10.73
Religious Identification [b]		
Agnostic	26	14.69
Atheist	16	9.04
Catholic	39	22.03
Christian	61	34.46
Muslim	1	0.56
Non-religious	23	12.99
Other	11	6.21
Educational Level [b]		
High school	36	20.34
GED	11	6.21
Bachelor's degree	72	40.68
Trade/Vocational degree	15	8.47
Graduate Degree	37	20.90
Other	6	3.39
Employment Status [b, c]		
Employed Full-time	137	42.02
Employed Part-time	111	34.05
Unemployed	78	23.92

Notes: Sample size differs due to funneling error in survey software as well as non-responses by participants, differences indicated as follows: a. n =326, b. sample size = 177, c. Data collection was within dates of US State shutdowns due to COVID-19 [03/08/2020 – 05/07/2020], therefore employment data may be biased by job-loss or furloughed workers.

Table 2: Caregiver Role and Burden Characteristics

	Current Caregivers (n = 326)	
	M	*SD*
Hours providing care weekly	36.04	30.13
ALDs Performed	6.72	2.37
IADLs Performed	6.90	1.53
Zarit Burden Inventory	41.99	17.40
Intent to Transfer [a]	4.05	2.08
Age of care recipient	78.04	8.47
Hours of sleep per night	6.40	1.84
Caregiver Role	*n*	*%*
Primary Caregiver	115	35.3
Equally Shared	123	37.7
Non-Primary	88	27.0
Housing		
Lives with CR	230	70.55
Lives within 20 minutes	48	14.72
Lives 20+ minutes away	48	14.72
Frequency of visits if living apart		
Daily	32	33.33
4-6 times per week	35	36.46
2-3 times per week	19	19.79
Once per week	4	4.17
1-3 times per month	3	3.13
Less than once per month	3	3.13
Work impacts related to caregiving [b]		
Yes	183	75.00
No	61	25.00
Child/Grandchild present in home		
Yes	123	37.73
No	203	62.27
Gender of Care Recipient [c]		
Male	68	38.64
Female	108	61.36

Notes: a. Intent to transfer measured on a 1-7 point Likert-style scale with 1 indicating strong intent to transfer and 7 indicating no plan to transfer; Sample size differs due to funneling error in survey software as well as non-responses by participants, differences indicated as follows: b.n = 244, c. n =176

Table 3: Psychometric Properties of ICBI-25 Items

Items	Coefficient Alpha	$S\text{-}X^2$
1. I feel worn out from caregiving.	1.57	92.13**
2. Spending time with the care recipient is difficult.	0.69	89.74
3. I feel motivated to be a caregiver every day. [R]	0.25	100.46
4. I have energy to complete most caregiving tasks. [R]	0.35	133.41**
5. I feel drained after several hours of caregiving.	1.38	99.17**
6. I feel burned out from caregiving.	1.95	62.13
7. I have time to take breaks from caregiving for myself. [R]	0.10	117.72
8. I had a choice to become a caregiver. [R]	0.16	86.36
9. Barring changes in care recipient health, I expect to remain a caregiver for the foreseeable future.	0.22	101.61
10. I do not have the time or energy to take care of myself.	0.89	78.91*
11. I feel physically drained.	2.32	65.60
12. Caregiving is physically exhausting.	1.45	81.20
13. I feel well-rested in the morning. [R]	0.42	121.42*
14. I often feel unwell.	1.09	78.72
15. I feel tired all the time.	1.91	65.13
16. I am irritable.	1.31	76.29
17. I feel emotionally drained.	2.06	62.77
18. Caregiving is emotionally exhausting.	1.49	75.23
19. I am satisfied with my life. [R]	0.33	104.14
20. I am often frustrated.	1.40	61.44
21. Caregiving puts me in a pleasant mood. [R]	0.30	115.63*
22. I don't have the energy to socialize.	1.05	75.47
23. I sometimes become angry with the person I am caring for.	0.45	108.90
24. I spend enjoyable time with other people. [R]	0.22	114.70
25. I have a good relationship with the person I am caring for. [R]	0.06	100.33*

*Note: * p<.05, **p<.001; S-X² = signed chi-squared test (Kang & Chen, 2007; Orlando & Thissen, 2000, 2003); (R) indicates reverse scores items*

Table 4: Degree of Agreement Between Measures

	t	p value
ICBI and CBI Difference Scores	-30.37	<.001
ICBI and CBI Personal Burnout	-46.89	<.001
ICBI and CBI Work Burnout	30.98	<.001
ICBI and CBI Client Burnout	38.46	<.001
ICBI and OLBI Difference Scores	14.27	<.001
ICBI and CESD Difference Scores	0.93	0.351

Note: To conduct Bland-Altman comparisons difference scores between each scale score were calculated, as well as the mean score of the two scales for each participant.

Table 5: Predictive Validity of Burnout Measures and Comparison of Correlations

	Burnout Scales	Correlation	Comparison of Correlation Coefficients	
			z	p
Intent to Transfer	ICBI	-0.20***		
	OLBI	-0.19**	0.22	0.826
	CBI Personal Burnout	-0.16*	0.60	0.549
	CBI Work Burnout	-0.24***	-0.52	0.603
	CBI Client Burnout	**-0.35***	**-1.97**	**0.049**
	ICBI	0.59***	z	p
Zarit Burden Inventory	OLBI	0.64***	-0.90	0.368
	CBI Personal Burnout	0.56***	0.68	0.497
	CBI Work Burnout	0.58***	0.25	0.803
	CBI Client Burnout	0.68***	-1.91	0.056
	ICBI	0.51***	z	p
Depression (CESD)	OLBI	0.52***	-0.24	0.810
	CBI Personal Burnout	0.51***	-0.02	0.984
	CBI Work Burnout	0.43***	1.30	0.194
	CBI Client Burnout	0.46***	0.78	0.435
	ICBI	-0.12*	z	p
Perceived Social Support	**OLBI**	**-0.41***	**-3.99**	**<0.001**
	CBI Personal Burnout	-0.15**	-0.44	0.660
	CBI Work Burnout	-0.08	0.41	0.682
	CBI Client Burnout	-0.20***	-1.07	0.285
	ICBI	-0.20	z	p
Social Desirability Bias (SDS-17)	OLBI	-0.30	-1.30	0.194
	CBI Personal Burnout	-0.15	0.69	0.490
	CBI Work Burnout	-0.24	-0.51	0.610
	CBI Client Burnout	-0.30	-1.29	0.197

*Note: *p < .01, **p < .05, ***p < .001; Comparison of correlation coefficients uses a fisher r-to-z transformation. Significant values indicate a noteworthy difference in the strength of correlations.*

Table 6: Test Information Comparisons of ICBI-10, CBI, and OLBI

Model	Total information (± 2 theta)	Total Information	Proportion (± 2 theta)	Items
ICBI	60.49	61.10	.99	10
OLBI	46.04	49.97	.92	16
CBI Client	44.57	44.77	.99	6
CBI Personal	51.90	52.26	.99	6
CBI Work	56.26	56.74	.99	7

Table 7: Correlation Between ICBI-10 and Caregiving Burden Factors

	r	p value
Weekly CG Hours	.12	.036
ADL Count	.31	<.001
IADL Count	.24	<.001
Zarit Burden Inventory	.59	<.001
Severe Burden Caregiver [a]	.44	<.001

a. Severe burden parameters are 20+ hours of caregiving per week and a score of 60+ on the ZBI

Table 8: Exploratory Factor Analysis of Items on the ICBI-10

Items	Component 1
I feel emotionally drained.	.821
I feel physically drained.	.814
I feel tired all the time.	.809
I feel burned out from caregiving.	.757
I am irritable.	.756
I often feel unwell.	.745
I am often frustrated.	.743
Caregiving is physically exhausting.	.707
Caregiving is emotionally exhausting.	.698
I do not have the time or energy to take care of myself.	.678

Notes: Extraction method: Eigenvalues over 1; Rotation method: None;
Loadings larger than .60 are in bold.

Table 9. Model Summaries for Mediation Analysis

Model	F	p	R^2
Caregiver Burden predicting Depression	$(1, 324) = 174.60$	$<.001$	.35
Caregiver Burden predicting Burnout	$(2, 323) = 110.17$	$<.001$	.41
Caregiver Burden and Burnout predicting Depression	$(1, 324) = 193.25$	$<.001$	.37

APPENDIX C: ICBI-25 ITEM FORM

Informal Caregiver Burnout Inventory (ICBI)

Instructions: Please select your level of agreement with the following statements. Please consider your experience as a caregiver over the last month, or since becoming a caregiver if it has been less than one month.

Burnout Questionnaire	Agree completely	Agree a little	Neither agree / disagree	Disagree a little	Disagree completely
1. I feel worn out from caregiving.					
2. Spending time with the care recipient is difficult.					
3. I feel motivated to be a caregiver every day. *(R)*					
4. I have energy to complete most caregiving tasks. *(R)*					
5. I feel drained after several hours of caregiving.					
6. I feel burned out from caregiving.					
7. I have time to take breaks from caregiving for myself. *(R)*					
8. I had a choice to become a caregiver. *(R)*					
9. Barring changes in care recipient health, I expect to remain a caregiver for the foreseeable future.					
10. I do not have the time or energy to take care of myself.					
11. I feel physically drained.					
12. Caregiving is physically exhausting.					
13. I feel well-rested in the morning. *(R)*					

14. I often feel unwell.					
15. I feel tired all the time.					
16. I am irritable.					
17. I feel <u>emotionally</u> drained.					
18. Caregiving is <u>emotionally</u> exhausting.					
19. I am satisfied with my life. ^(R)					
20. I am often frustrated.					
21. Caregiving puts me in a pleasant mood. ^(R)					
22. I don't have the energy to socialize.					
23. I sometimes become angry with the person I am caring for.					
24. I spend enjoyable time with other people. ^(R)					
25. I have a good relationship with the person I am caring for. ^(R)					
Support Questionnaire	**Agree completely**	**Agree a little**	**Neither agree / disagree**	**Disagree a little**	**Disagree completely**
26. I am supported in my caregiving efforts by community support groups or assistance services.					
27. The support I receive from community support groups or assistance services makes it easier to provide care.					

28. I am supported in my caregiving efforts by friends/family.					
29. The support I receive from friends/family makes it easier to provide care.					
30. My support network lessens the burden of caregiving					
31. My support network allows me to take breaks from caregiving					

Note: core exhaustion = 1 - 9; physical exhaustion = 10 - 14; mental exhaustion = 15 - 21; social exhaustion = 22 - 25; perceived support = 26 - 31. Perceived support scored separately from burnout inventory. (R) indicates Reverse scored items.

APPENDIX D: ICBI-10 ITEM FORM

Informal Caregiver Burnout Inventory (ICBI)

Instructions: Please select your level of agreement with the following statements. Please consider your experience as a caregiver over the last month, or since becoming a caregiver if it has been less than one month.

Burnout Questionnaire	Agree completely	Agree a little	Neither agree / disagree	Disagree a little	Disagree completely
1. I feel burned out from caregiving.					
2. I do not have the time or energy to take care of myself.					
3. I feel physically drained.					
4. Caregiving is physically exhausting.					
5. I often feel unwell.					
6. I feel tired all the time.					
7. I am irritable.					
8. I feel emotionally drained.					
9. Caregiving is emotionally exhausting.					
10. I am often frustrated.					
Support Questionnaire	**Agree completely**	**Agree a little**	**Neither agree / disagree**	**Disagree a little**	**Disagree completely**
1. My caregiving is supported by support groups or professional services.					
2. The support I receive from these services lessen my burden.					
3. My caregiving is supported by friends/family.					
4. The support I receive from friends/family lessen my burden.					

APPENDIX E: EXPERT FEEDBACK FORM

Informal Caregiver Burnout Inventory (ICBI)

For the following questions, please indicate your level of agreement that each item is:

Appropriate: Items that are appropriate should be relevant to the experiences of caregivers, do not appear biased, and are not likely to cause a negative reaction to those answering it.

Worded clearly: Items that are worded clearly are easy to understand and unlikely to be misinterpreted.

Please grade both areas on a 1 – 10 scale where:
  1 indicates the item is extremely inappropriate or unclear.
  5 indicates a moderate level of appropriateness or clarity.
  10 indicates the item is highly appropriate or clear.

For any item you believe is inappropriate or unclear please provide a comment as to why you believe so. You may include a re-worded version of the question.

Burnout Questionnaire	Item is appropriate (1-10)	Item is worded clearly (1-10)
1. I feel worn out from caregiving		
2. Spending time with the care recipient is difficult		
3. I feel motivated every day		
4. I have energy to complete caregiving task		
5. I feel drained after a day of caregiving		
6. I feel burned out		
7. I have time to take breaks for myself		
8. I had a choice to become a caregiver		
9. I expect to remain a caregiver for the foreseeable future		
10. I forget or do not have the energy to take care of myself		
11. I feel <u>physically</u> drained		
12. Caregiving is <u>physically</u> exhausting		
13. I feel well-rested in the morning		
14. I often feel ill		
15. I feel tired all the time		
16. I am irritable		
17. I feel <u>mentally</u> drained		

18. Caregiving is <u>mentally</u> exhausting		
19. I am satisfied with my life		
20. I am often frustrated		
21. I feel pleasant emotions while caregiving		
22. I don't have the energy to socialize		
23. I sometimes become mad with the person I care for		
24. I spend enjoyable time with other people		
25. I have a good relationship with the care recipient		

Please indicate if you are a:
> Past caregiver
> Current caregiver
> Related professional expert
> Both caregiver and related professional expert

APPENDIX F: CAREGIVER SCREENER

1. What is your age?
2. Do you currently provided unpaid care to a friend, family member, or loved one over the age of 18?
    a. Yes
    b. No
3. Thinking of the individual you care for, which best fits the <u>main</u> problem or illness they experienced?
    a. Cancer
    b. Arthritis
    c. Back problems
    d. Blood pressure, hypertension
    e. Brain damage or injury
    f. Broken bones
    g. Alzheimer's, confusion, dementia, forgetfulness
    h. Developmental or intellectual disorder, mental retardation, Down syndrome
    i. Diabetes
    j. Feeble, unsteady, failing
    k. Hearing loss, deafness
    l. Heart disease, heart attack
    m. Lung disease, emphysema, COPD
    n. Mental illness, emotional illness, depression
    o. Mobility problem, can't get around
    p. Old age, Aging
    q. Stroke
    r. Substance, drug, alcohol use
    s. Surgery, wounds
    t. Vision loss, blindness, can't see well
    u. Other [Specify]
    v. Not sure. . .

APPENDIX G: CAREGIVER BACKGROUND AND CIRCUMSTANCES

Throughout this survey the individual you care or cared for in the past will be referred to as the "care recipient." Please answer each question to the best of your ability thinking of the time you provided unpaid assistance to this individual with dementia or dementia-related difficulty.

1. What is your biological sex?
    a. Male
    b. Female
2. What is your gender?
    a. Male
    b. Female
    c. Transgender
    d. Gender non-conforming
    e. Prefer not to answer
    f. Other (Please specify):
3. Which race and/or ethnicity best describes you? (Please check all that apply)
    a. Asian
    b. Black or African American
    c. Hispanic/Latina(o)
    d. Native American
    e. Native Hawaiian/Pacific Islander
    f. White
    g. Other (Please specify):
    h. Prefer not to answer.
4. What is your current relationship status?
    a. Married
    b. Divorced
    c. Separated
    d. Widowed
    e. Living with a partner
    f. Single, never married
    g. With a partner, not living together
5. What is sexual orientation?
    a. Straight
    b. Gay or lesbian
    c. Bisexual
    d. Pansexual
    e. Asexual
    f. Other (Please specify):
6. What is your educational level?
    a. Elementary school
    b. High school
    c. GED
    d. Bachelor's Degree

  e. Trade/Vocational degree
  f. Master's Degree
  g. Professional degree (Ph.D., M.D., D.O., J.D.)
  h. Other (Please specify):
7. How many adults do you provide unpaid care for? (Funneling: give options based on number) ____
8. What is the gender of this care recipient?
  a. Male
  b. Female
9. What age is the <u>care recipient</u>? ____
10. Where does the care recipient live in relation to you?
  a. In the same household
  b. Within twenty minutes of your home
  c. Between twenty minutes and an hour from your home
  d. One or two hours from your home
  e. More than two hours away
11. [Funnel if not in the same household] On average, how often do you visit the care recipient?
  a. 5+ times a week
  b. 3-5 times a week
  c. 2-3 times a week
  d. Once a week
  e. A few times a month
  f. Once a month
  g. Few times a year
  h. Less often
12. How long have you been providing care to this individual? (Please give your best estimate in months and years)
13. On average, how many hours do you spend providing care each week? _____
14. Is the care recipient using professional care services? *Circle any and all that apply.*
  a. Yes, respite care (adult day care)
  b. Yes, home health nurse/care aids
  c. Yes, lives in an assisted living facility
  d. Yes, lives in a nursing home

15. Do you share care responsibilities with anyone else (unpaid or professional)?
  e. Yes, and I provide the majority of care (more than 50%)
  f. Yes, and I share responsibilities with others (50% or less)
  g. No, I am the sole caregiver (100% of care)
16. Do you live with the care recipient? (Yes/No) [If "Yes" 17]
  h. How often do you travel to provide care for this individual?
    i. Daily
    ii. 4-6 times per <u>week</u>
    iii. 2-3 times per <u>week</u>
    iv. Once per <u>week</u>
    v. 1-3 times per <u>month</u>

      vi. Less than once per <u>month</u>
   i. How many minutes does it take to travel to their location? _____
17. Are you currently employed? (Yes/No) [If "No" 18]
   j. How many hours do you work per week? _____
   k. Have you found it difficult to balance work and caregiving responsibilities?
      i. Yes, very difficult
      ii. Yes, moderately difficult
      iii. Yes, a little difficult
      iv. No, not difficult
   l. Have caregiving responsibilities interfered with your work (for example, having to reduce hours working, missing work, or lower work quality)?
      i. Yes
      ii. No
18. Do you care for any other dependent individuals on a regular basis?
   m. Yes, children [Number ___]
   n. Yes, adults [Number ___]
   o. No
   p. How many hours do you spend providing care for these individuals per week?
   q. Have you found it difficult to balance caregiving responsibilities between these individuals?
      i. Yes, very difficult
      ii. Yes, moderately difficult
      iii. Yes, a little difficult
      iv. No, not difficult
19. On average, how many hours of sleep do you get each night?

APPENDIX H: LEVEL OF CARE INDEX

Caregiving Role and Responsibilities

Thinking of the individual you provide care for, please indicate what level of assistance, if any, you provide for each task.

ADLs	No Assistance	Some Assistance	Complete Assistance	Not Applicable
1. Bathing				
2. Dressing				
3. Grooming				
4. Oral Care				
5. Toileting				
6. Transferring				
7. Walking				
8. Climbing Stairs				
9. Eating				
10. How difficult is it to complete these tasks?	Not difficult at all	A little difficult	Moderately difficult	Very difficult
11. How stressful is it to complete these tasks?	Not at all stressful	A little stressful	Moderately stressful	Very stressful
IADLs	**No Assistance**	**Some Assistance**	**Complete Assistance**	**Not Applicable**
12. Shopping				
13. Cooking				
14. Managing Medications				
15. Uses the Phone				
16. Housework				
17. Laundry				
18. Driving				
19. Managing Finances				
20. How difficult is it to complete these tasks?	Not difficult at all	A little difficult	Moderately difficult	Very difficult
21. How stressful is it to complete these tasks?	Not at all stressful	A little stressful	Moderately stressful	Very stressful
Note: Questions 1 - 9 and 12 - 19 adapted from the Activities of Daily Living Checklist (PBS & AARP, 2008)				

APPENDIX I: ZARIT BURDEN INVENTORY

The Zarit Burden Inventory

Please circle the response that best describes how you feel.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
Do you feel that your relative asks for more help than he/she needs?					
Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?					
Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?					
Do you feel embarrassed over your relative's behavior?					
Do you feel angry when you are around your relative?					
Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?					
Are you afraid what the future holds for your relative?					
Do you feel your relative is dependent on you?					
Do you feel strained when you are around your relative?					
Do you feel your health has suffered because of your involvement with your relative?					
Do you feel that you don't have as much privacy as you would like because of your relative?					
Do you feel that your social life has suffered because you are caring for your relative?					
Do you feel uncomfortable about having friends over because of your relative?					
Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?					
Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?					

Do you feel that you will be unable to take care of your relative much longer?					
Do you feel you have lost control of your life since your relative's illness?					
Do you wish you could leave the care of your relative to someone else?					
Do you feel uncertain about what to do about your relative?					
Do you feel you should be doing more for your relative?					
Do you feel you could do a better job in caring for your relative?					
Overall, how burdened do you feel in caring for your relative?					

Interpretation of Score:

        0 - 21 little or no burden

        21 - 40 mild to moderate burden

        41 - 60 moderate to severe burden

        61 - 88 severe burden

APPENDIX J: COPENHAGEN BURNOUT INVENTORY

Copenhagen Burnout Inventory *(English version)*

Part one: Personal Burnout					
1. How often do you feel tired?	Always	Often	Sometimes	Seldom	Never / almost never
2. How often are you physically exhausted?	Always	Often	Sometimes	Seldom	Never / almost never
3. How often are you emotionally exhausted?	Always	Often	Sometimes	Seldom	Never / almost never
4. How often do you think: "I can't take it anymore"?	Always	Often	Sometimes	Seldom	Never / almost never
5. How often do you feel worn out?	Always	Often	Sometimes	Seldom	Never / almost never
6. How often do you feel weak and susceptible to illness?	Always	Often	Sometimes	Seldom	Never / almost never
Part two: Work-related burnout					
1. Is your caregiving emotionally exhausting?	To a very high degree	To a high degree	Somewhat	To a low degree	To a very low degree
2. Do you feel burnt out because of your caregiving?	To a very high degree	To a high degree	Somewhat	To a low degree	To a very low degree
3. Does your caregiving frustrate you?	To a very high degree	To a high degree	Somewhat	To a low degree	To a very low degree
4. Do you feel worn out at the end of a day caregiving?	Always	Often	Sometimes	Seldom	Never / almost never
5. Are you exhausted in the morning at the thought of another day of caregiving?	Always	Often	Sometimes	Seldom	Never / almost never

6. Do you feel that every caregiving hour is tiring for you?	Always	Often	Sometimes	Seldom	Never / almost never
*7. Do you have enough energy for family and friends during leisure time?	Always	Often	Sometimes	Seldom	Never / almost never
Part three: Client-related burnout					
1. Do you find it hard to care for the care recipient?	To a very high degree	To a high degree	Somewhat	To a low degree	To a very low degree
2. Do you find it frustrating to care for the care recipient?	To a very high degree	To a high degree	Somewhat	To a low degree	To a very low degree
3. Does it drain your energy to work with the care recipient?	To a very high degree	To a high degree	Somewhat	To a low degree	To a very low degree
4. Do you feel that you give more than you get back when you work with the care recipient?	To a very high degree	To a high degree	Somewhat	To a low degree	To a very low degree
5. Are you tired of caring for the care recipient?	Always	Often	Sometimes	Seldom	Never / almost never
6. Do you sometimes wonder how long you will be able to continue providing care for the care recipient?	Always	Often	Sometimes	Seldom	Never / almost never
*Note: work-related turns adapted into caregiving-related terms (e.g., "work" substituted for "caregiving"); As advised in original study items will be randomized and sub-sections will not be labeled; *indicates that an item is reverse scored*					

APPENDIX K: OLDENBURG BURNOUT INVENTORY

Oldenburg Burnout Inventory

Instruction: Below you find a series of statements with which you may agree or disagree. Using the scale, please indicate the degree of your agreement by selecting the number that corresponds with each statement.

	Strongly Agree	Agree	Disagree	Strongly Disagree
1. I always find new and interesting aspects in my caregiving	1	2	3	4
2. There are days when I feel tired before I begin my caregiving.	1	2	3	4
3. It happens more and more that I talk about my caregiving in a negative way.	1	2	3	4
4. After caregiving, I tend to need more time than in the past in order to relax and feel better.	1	2	3	4
5. I can tolerate the pressure of my caregiving very well.	1	2	3	4
6. Lately, I tend to think less when caregiving and do it almost mechanically.	1	2	3	4
7. I find my caregiving to be a positive challenge.	1	2	3	4
8. During my caregiving, I often feel emotionally drained.	1	2	3	4
9. Over time one can become disconnected from this type of caregiving.	1	2	3	4
10. After my caregiving, I have enough energy for my leisure activities.	1	2	3	4
11. Sometimes I feel sickened by my caregiving tasks.	1	2	3	4
12. After my caregiving, I usually feel worn out and weary.	1	2	3	4
13. This is the only type of caregiving I can imagine myself doing.	1	2	3	4
14. Usually, I can manage the amount of caregiving well.	1	2	3	4
15. I feel more and more engaged in my caregiving.	1	2	3	4
16. When I am caregiving, I usually feel energized.	1	2	3	4
Note: Adapted from original OLBI, the term "work" has been replaced with "caregiving"; Disengagement items are 1, 3(R), 6(R), 7, 9(R), 11(R), 13, 15. Exhaustion items are 2(R), 4(R), 5,8(R), 10, 12(R), 14, 16. (R) means reversed item when the scores should be such that higher scores indicate more burnout.				

APPENDIX L: CENTER FOR EPIDEMIOLOGIC STUDIES DEPRESSION SCALE

Center for Epidemiologic Studies Depression Scale (CES-D)

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week

	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
1. I was bothered by things that usually don't bother me.				
2. I did not feel like eating; my appetite was poor.				
3. I felt that I could not shake off the blues even with help from my family or friends				
4. I felt I was just as good as other people.				
5. I had trouble keeping my mind on what I was doing.				
6. I felt depressed.				
7. I felt that everything I did was an effort				
8. I felt hopeful about the future				
9. I thought my life had been a failure.				
10. I felt fearful.				
11. My sleep was restless.				
12. I was happy				
13. I talked less than usual.				
14. I felt lonely.				
15. People were unfriendly				
16. I enjoyed life				
17. I had crying spells.				
18. I felt sad.				
19. I felt that people dislike me.				
20. I could not get "going."				

APPENDIX M: SOCIAL DESIRABILITY SCALE

The Social Desirability Scale-17

Instruction

Below you will find a list of statements. Please read each statement carefully and decide if that statement describes you or not. If it describes you, check the word "true"; if not, check the word "false".

Items

1. I sometimes litter.
2. I always admit my mistakes openly and face the potential negative consequences.
3. In traffic I am always polite and considerate of others.
4. I have tried illegal drugs (for example, marijuana, cocaine, etc.).
5. I always accept others' opinions, even when they don't agree with my own.
6. I take out my bad moods on others now and then.
7. There has been an occasion when I took advantage of someone else.
8. In conversations I always listen attentively and let others finish their sentences.
9. I never hesitate to help someone in case of emergency.
10. When I have made a promise, I keep it--no ifs, ands or buts.
11. I occasionally speak badly of others behind their back.
12. I would never live off other people.
13. I always stay friendly and courteous with other people, even when I am stressed out.
14. During arguments I always stay objective and matter-of-fact.
15. There has been at least one occasion when I failed to return an item that I borrowed.
16. I always eat a healthy diet.
17. Sometimes I only help because I expect something in return.

Note: Answer categories are "true" (1) and "false" (0). Items 1, 4, 6, 7, 11, 15, and 17 are reverse keyed. Item 4 was deleted from the final version of the SDS-17.

APPENDIX N: IRB APPROVAL OF HUMAN RESEARCH EXPERT FEEDBACK

UNIVERSITY OF CENTRAL FLORIDA

EXEMPTION DETERMINATION

February 6, 2020

Dear Nicholas James:

On 2/6/2020, the IRB determined the following submission to be human subjects research that is exempt from regulation:

Type of Review:	Initial Study, Exempt Category
Title:	Caregiver Burnout Scale Item Feedback
Investigator:	Nicholas James
IRB ID:	STUDY00001397
Funding:	None
Grant ID:	None

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made, and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request so that IRB records will be accurate.

If you have any questions, please contact the UCF IRB at 407-823-2901 or irb@ucf.edu. Please include your project title and IRB number in all correspondence with this office.

Sincerely,

Kamille Birkbeck
Designated Reviewer

APPENDIX O: IRB APPROVAL OF HUMAN RESEARCH SCALE VALIDATION

Institutional Review Board
FWA00000351
IRB00001138
Office of Research
12201 Research Parkway
Orlando, FL 32826-3246

<u>EXEMPTION DETERMINATION</u>

January 15, 2020

Dear Nicholas James:

On 1/15/2020, the IRB determined the following submission to be human subjects research that is exempt from regulation:

Type of Review:	Initial Study, Exempt Category
Title:	Development of Informal Caregiver Burnout Inventory
Investigator:	Nicholas James
IRB ID:	STUDY00001173
Funding:	None
Grant ID:	None

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made, and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request so that IRB records will be accurate.

If you have any questions, please contact the UCF IRB at 407-823-2901 or irb@ucf.edu. Please include your project title and IRB number in all correspondence with this office.

Sincerely,

Kamille C. Birkbeck

Kamille Birkbeck
Designated Reviewer

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