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# Implementing an Online, Integrative, Multi-Component, Group-Based Cognitive Behavior Therapy (CBT) for the Reduction of Caregiver Burden in Primary Familial Caregivers of Persons with Dementia: A Preliminary Test of Feasibility

Daniel Robert Schaffer  
*Old Dominion University, dscha002@odu.edu*

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**IMPLEMENTING AN ONLINE, INTEGRATIVE, MULTI-COMPONENT,  
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FOR THE REDUCTION OF CAREGIVER BURDEN IN  
PRIMARY FAMILIAL CAREGIVERS OF PERSONS WITH DEMENTIA:  
A PRELIMINARY TEST OF FEASIBILITY**

by

Daniel Robert Schaffer  
B.S. May 2014, Barton College  
M.S. August 2018, Old Dominion University

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Approved by:

Dr. Jennifer Flaherty (Director)

Dr. Serina Neumann (Member)

Dr. Cathy Lau-Barraco (Member)

Dr. Richard Handel (Member)

## **ABSTRACT**

### **IMPLEMENTING AN ONLINE, INTEGRATIVE, MULTI-COMPONENT, GROUP-BASED COGNITIVE BEHAVIOR THERAPY (CBT) FOR THE REDUCTION OF CAREGIVER BURDEN IN PRIMARY FAMILIAL CAREGIVERS OF PERSONS WITH DEMENTIA: A PRELIMINARY TEST OF FEASIBILITY**

Daniel Robert Schaffer, M.S.

Virginia Consortium Program in Clinical Psychology, 2022

Director: Dr. Jennifer Flaherty

The purpose of this study was to examine the preliminary feasibility of an online, manualized, group-based, multi-component, cognitive behavioral therapy (CBT) treatment approach for the reduction of caregiver burden among family caregivers of persons with dementia. This study had five primary hypotheses: (1) the recruitment plan, as outlined within this study, would yield the target number of participants within a 12-month period; (2) the proposed group therapy protocol would produce a positive therapeutic climate, as operationalized by increased levels of perceived social support, perceived group cohesion, positive therapeutic alliance, and positive engagement; (3) this study would maintain adequate participant retention, as operationalized by at least 80% of participants enrolled completing the entire course of treatment; (4) the online CBT group therapy would produce positive levels of satisfaction towards the therapy among group members; and (5) the proposed protocol would not create significant levels of perceived burdensomeness among participants. An additional exploratory hypothesis in this study was that the manualized protocol would produce significant reductions in overall levels of caregiver burden, anxious symptoms, depressive symptoms, and role captivity among participants.

Dementia is a growing phenomenon around the world, and more families are choosing to provide informal at-home care for their loved-ones with dementia. While this removes financial burden and strain from institutions, it places a significant amount of stress, burden, and strain

(physical, psychological, and financial) on the family caregivers. Caregiver burden, also referred to as caregiver burnout, is defined as the overall impact of the physical, psychological, social, and financial demands of caregiving. Caregiver burden is often associated with increased rates of depression, anxiety, psychotropic drug use, somatic disorders, and physical health concerns. With family members becoming primary caregivers to persons with dementia at increasing rates, so too are the experiences of caregiver burden. While interventions do exist for caregivers experiencing high levels of burden, many of these interventions are either (a) not efficacious, (b) not cost-effective, or (c) not flexible enough to work within the various constraints of caregiving. It is clear that this population is in need of an efficacious and cost-effective treatment approach for the reduction of caregiver burden.

Results from this study were ultimately inconclusive for supporting feasibility of the research and treatment protocol as a whole; however, certain aspects of the data did suggest some potential areas for preliminary feasibility such as clinically significant improvement in group cohesion and caregiver burden scores across treatment time. It is strongly recommended that further studies continue to examine the preliminary feasibility of this treatment protocol and to explore areas in which accessibility to this intervention plan may be improved in order to better serve caregivers of persons with dementia.

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This dissertation is dedicated to all those without whom I could not have made it this far. To my parents, Matthew and Cynthia Schaffer, for supporting me in this educational journey and for always being a phone call away; to my mentor, Dr. Serina Neumann, for all of your guidance, advice, and encouragement; to the amazing clinical supervisors who have pushed and challenged me in my clinical and educational growth; and of course, to my amazing wife and partner in life Lillian Sarvey – for even in the face of physical distance, you were always right by my side supporting and encouraging me every step of the way.

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## TABLE OF CONTENTS

	Page
LIST OF TABLES .....	x
LIST OF FIGURES .....	xi
Chapter	
I. INTRODUCTION .....	1
CAREGIVER BURDEN .....	1
TREATMENTS AND INTERVENTIONS TARGETING CAREGIVER BURDEN IN DEMENTIA CAREGIVERS .....	9
CONSIDERATIONS FOR ONLINE GROUP THERAPIES .....	20
ETHICAL AND LEGAL CONCERNS OF ONLINE PSYCHOTHERAPY .....	21
ONLINE THERAPY COMPARED TO IN-PERSON THERAPIES .....	23
GROUP PROCESSES IN ONLINE GROUP THERAPIES: THE ONLINE GROUP CLIMATE.....	23
ONLINE THERAPIES FOR CAREGIVER BURDEN .....	27
COGNITIVE BEHAVIORAL THERAPY (CBT).....	28
COGNITIVE BEHAVIORAL THERAPY (CBT) FOR CAREGIVER BURDEN .....	32
EMPIRICALLY INFORMED CONCEPTUALIZATION OF CAREGIVER BURDEN: INFORMATION-PROCESSING THEORY AND SOCIAL LEARNING THEORY.....	34
STATEMENT OF PURPOSE & STUDY AIMS.....	37
HYPOTHESES .....	39
II. METHOD .....	42
SAMPLE.....	42
INSTITUTIONAL REVIEW.....	42
PROCEDURES.....	43
TREATMENT CONDITION: CBT GROUP TREATMENT .....	43
CBT SESSION ONE .....	44
CBT SESSION TWO .....	45
CBT SESSION THREE.....	45
CBT SESSION FOUR.....	46
CBT SESSION FIVE AND SIX.....	47
CBT SESSION SEVEN.....	49
CBT SESSION EIGHT.....	49
RECRUITMENT OF PARTICIPANTS.....	50



	Page
PARTICIPANT RETENTION PLAN.....	53
SUPERVISION PLAN .....	55
RISK ASSESSMENT AND EVALUATION .....	57
STUDY TIMELINE .....	59
INSTRUMENTS.....	61
SOCIAL PROVISION SCALE (SPS).....	61
THERAPEUTIC FACTORS INVENTORY, COHESION SCALE (TFI-COH) .....	62
WORKING ALLIANCE INVENTORY, SHORT FORM (WAI-SF).....	63
GROUP ATTITUDE SCALE (GAS).....	64
SATISFACTION WITH THERAPY & THERAPIST SCALE REVISED (STTS-R) .....	65
MODIFIED PERCEIVED RESEARCH BURDEN ASSESSMENT (MPRBA) .....	65
CAREGIVER BURDEN INVENTORY (CBI).....	66
HOSPITAL ANXIETY & DEPRESSION SCALE (HADS).....	68
ROLE CAPTIVITY SCALE (RCS) .....	69
DEMOGRAPHICS QUESTIONNAIRE.....	71
ASSESSMENT SCHEDULE .....	71
III. RESULTS .....	73
SUMMARY OF RECRUITMENT .....	73
SAMPLE DEMOGRAPHICS .....	74
RELIABILITY OF MEASURES .....	75
RESEARCH QUESTION ONE .....	75
HYPOTHESIS ONE.....	76
HYPOTHESIS TWO .....	78
HYPOTHESIS THREE .....	84
HYPOTHESIS FOUR .....	85
HYPOTHESIS FIVE .....	87
RESEARCH QUESTION TWO.....	89
HYPOHTESIS SIX.....	89
IV. DISCUSSION.....	96
LIMITATIONS AND FUTURE CONSIDERATIONS .....	103
CONCLUSIONS.....	112
REFERENCES .....	114
APPENDICES	
A. INFORMED CONSENT FORM.....	151

	Page
B. CAREGIVER BURDEN INVENTORY (CBI).....	156
C. HOSPITAL ANXIETY AND DEPRESSION SCALE (HADS) .....	157
D. ROLE CAPTIVITY SCALE (RCS) .....	158
E. SOCIAL PROVISIONS SCALE (SPS) .....	159
F. THERAPEUTIC FACTORS INVENTORY, COHESION SCALE (TFI-COH) .....	160
G. WORKING ALLIANCE INVENTORY, SHORT FORM (WAI-SF).....	161
H. GROUP ATTITUDE SCALE (GAS).....	162
I. DEMOGRAPHICS QUESTIONNAIRE.....	163
J. SCREENING QUESTIONNAIRE.....	166
K. CBT SESSION ONE .....	167
L. CBT SESSION TWO .....	170
M. CBT SESSION THREE.....	173
N. CBT SESSION FOUR.....	176
O. CBT SESSIONS FIVE AND SIX .....	179
P. CBT SESSION SEVEN.....	182
Q. CBT SESSION EIGHT.....	184
R. CAREGIVER STRESS SYMPTOM CHECKLIST.....	185
S. PLEASANT ACTIVITIES PLANNING SHEET .....	186
T. COGNITIVE DISTORTIONS.....	187
U. THOUGHT RECORD (PART ONE).....	188
V. THOUGHT RECORD (PART TWO).....	189
W. 20 QUESTIONS TO CHALLENGE NEGATIVE THOUGHTS .....	190
X. SATISFACTION WITH THERAPY AND THERAPIST SCALE, REVISED (STTS-R).....	191
Y. MODIFIED PERCEIVED RESEARCH BURDEN ASSESSMENT (MPRBA) .....	192
VITA.....	193

## LIST OF TABLES

Table	Page
1. Systematic Review of Existing Treatments for Caregiver Burden in Primary Family Caregivers of Persons with Dementia .....	15
2. Assessment Schedule .....	72
3. Summary of Recruitment Data .....	77
4. Descriptive Statistics, Group Climate Measures .....	79
5. Skewness & Kurtosis Statistics for Group Climate Measures .....	80
6. Wilcoxon Signed-Rank Test Results, Group Climate Measures .....	81
7. Descriptive Statistics, STTS-R Items and Scales .....	86
8. Descriptive Statistics, mPRBA .....	88
9. Descriptive Statistics, Symptom and Outcome Measures .....	90
10. Skewness and Kurtosis Values for Outcome Measures, Pre- and Post-Treatment .....	91
11. Wilcoxon Signed Rank Test Results, Outcome Measures .....	92

## LIST OF FIGURES

FIGURE	Page
1. Social Provisions Scale (SPS), baseline to end of treatment scatterplot.....	82
2. Therapeutic Factors Inventory Cohesion Scale (TFI-Coh), baseline to end of treatment scatterplot.....	82
3. Working Alliance Inventory Short Form (WAI-SF), baseline to end of treatment scatterplot.....	83
4. Group Attitudes Scale (GAS), baseline to end of treatment scatterplot.....	83
5. Caregiver Burden Inventory (CBI), baseline to end of treatment scatterplot.....	92
6. Hospital Anxiety and Depression Scale anxiety subscale (HADS-A), baseline to end of treatment scatterplot .....	93
7. Hospital Anxiety and Depression Scale depression subscale (HADS-D), baseline to end of treatment scatterplot .....	93
8. Role Captivity Scale (RCS), baseline to end of treatment scatterplot .....	94

## CHAPTER I

### INTRODUCTION

#### Caregiver Burden

Caregiver burden, also referred to as caregiver burnout, is a multidimensional construct (Novak & Guest, 1989; Savundranayagam et al., 2010) defined as: “the overall impact of the physical, psychological, social, and financial demands of caregiving” (Marvardi et al., 2005, p. 46), and it is a condition that often arises among those providing care for individuals with chronic illnesses (Adelman et al., 2014). In the context of various chronic illnesses and disabilities, caregiver burden has been studied among caregivers for stroke survivors (Zorowitz et al., 2013), cancer patients (Higginson et al., 2010), mental illnesses such as bipolar disorder (Beentjes et al., 2012), schizophrenia (Möller-Leimkühler & Wiesheu, 2012), and PTSD (Klarić et al., 2010), traumatic brain injury (Shepherd-Banigan et al., 2018), chronic neurological disorders (Bartolo et al., 2010), chronic heart failure (Ågren et al., 2011), people with chronic health impairments post intensive hospital care (Haines et al., 2015), dementia (Adelman et al., 2014), and various other chronic illnesses (Savundranayagam et al., 2010). Regardless of care-recipient diagnosis, caregivers who experience caregiver burden are at greater risk for declining physical health, psychological health, quality of life, and greater risk of mortality (Limpawattana et al., 2012). While caregiver burden can, and should, be studied within the individual contexts of these various chronic illnesses, this proposed study will focus specifically on caregiver burden among primary caregivers for persons with dementia diagnoses.

Dementia, also known as Major Neurocognitive Disorder (major NCD), is a growing phenomenon around the world. According to the World Health Organization (WHO, 2015), the number of people living with dementia diagnoses in 2015 was approximately 47.47 million

people. This number is projected to increase to approximately 76.36 million people worldwide in 2030 – a 60.86% increase – and up to 135.46 million people worldwide in 2050 – a 77.40% increase from 2030 and a 185.36% increase from 2015. This increase in prevalence rates is likely due to the growing population and increasing life expectancy of the general population (Alexopolous & Kelly, 2009; Alzheimer’s Association, 2016; Kelly & Petersen, 2007; NIA et al., 2015; Rabey & Dobrenovsky, 2016; Saykin & Rabin, 2014). Clearly the projected increase in dementia prevalence rates constitutes a serious issue around the world.

It should be noted that the precise prevalence rates of specific types of dementia disorders vary throughout the literature due to a lack of methodological uniformity and consistency in diagnostic criteria used across studies (Rizzi et al., 2014). The Alzheimer’s Association (2016) reports that Alzheimer’s disease comprises a majority of all dementia diagnoses, with approximately 60-80% of all dementia diagnoses being that of the Alzheimer’s type (more conservative estimates place Alzheimer’s disease closer to the 60% end of that range; Rizzi et al., 2014). Vascular dementia appears to be the second most prevalent form of dementia, comprising approximately 20% of all cases (Rizzi et al., 2014); frontotemporal dementia comprises approximately 2.7% of cases (Hogan et al., 2016); Lewy body dementia comprises approximately 4.6% of cases (Kane et al., 2018); specific statistics of Parkinson’s disease either vary widely or are unreliable due to large-scale diagnostic inconsistencies between studies and diagnostic difficulty (e.g., true Parkinson’s disease vs. parkinsonian disorders such as substance induced parkinsonism, vascular causes, progressive supranuclear palsy, and others; Muangpaisan et al., 2011). Prevalence rates also become difficult to specify due to the potential comorbidity between dementia disorders. In an autopsy study comprising of 1,700 individuals diagnosed with some form of dementia, Jellinger (2010) found that 80% of corpses displayed

Alzheimer's pathology; however, only 45.7% demonstrated only (i.e., "pure") Alzheimer's pathology. Additionally, while evidence of vascular dementia was found in 23.8% of autopsied corpses, 5.2% demonstrated vascular dementia along with signs of other forms of dementia as well (Jellinger, 2010).

Dementia, as a phenomenon, produces a significant financial strain. On the whole, dementia diagnoses have been shown to generate an average annual monetary cost per person of USD\$42,746 to USD\$56,290; when adjusting for comorbid medical conditions, persons with dementia are expected to incur USD\$28,501 of additional yearly medical costs (Hurd et al., 2013). Additionally, a Swedish study reported that a one-point decrease in scores on the Mini Mental State Exam (MMSE), a brief neurocognitive screening tool, was associated with an average increase in healthcare costs for that individual by approximately USD\$2,000/year (Wimo & Winblad, 2003). It should be noted that projected monetary costs of dementia tend to vary greatly among the literature due to differences in how medical care and the value of such care is assessed (Hurd et al., 2013). Regardless, it remains clear that dementia poses a significant financial burden both on the individual and societal levels. In addition to financial strain, caring for individuals with dementia diagnoses poses significant occupational, social, and emotional strain as well (Marvardi et al., 2005).

According to the Alzheimer's Association annual report (2018), 16.1 million family and other unpaid caregivers provided an estimated 18.4 billion hours of unpaid care for individuals with dementia – the equivalent of an average 21.9 hours per caregiver per week – in 2017 alone. It was projected that this amount of unpaid care was roughly equivalent to an economic value of 232.1 billion USD\$ (Alzheimer's Association, 2018). While 45% of unpaid or family caregivers

described caregiving as a rewarding experience, caregivers as a whole are significantly more likely to report elevations in general stress and strain (Alzheimer's Association, 2018).

Approximately 70% of people diagnosed with any form of dementia in the United States are cared for in the community by family members or friends (Black et al., 2013) – this number is expected to increase exponentially as the aging population grows larger. As a result, it is vital to explore treatments and interventions designed to reduce caregiver burden among this population.

Studies have indicated that approximately 32% of caregivers demonstrate significantly elevated levels of caregiver burden (Adelman et al., 2014). Risk factors of caregiver burden include, but may not be limited to: female sex, lower education level, living with the care receiver, pre-existing depressive symptoms, social isolation, financial stressors, more time spent providing care, and the perceived lack of choice in assuming the role of caregiver (Adelman, et al, 2014). Relationship satisfaction between the caregiver and care-recipient before the assumption of the caregiver-care-recipient dyad is also negatively correlated with the caregiver's experience of caregiver burden (Steadman et al., 2007). The prevalence and severity of behavioral and psychological symptoms of dementia (BPSDs) experienced in the care-recipient is also directly correlated with the caregiver's experience of caregiver burden (Black & Almeida, 2004; Ornstein & Gaugler, 2012; Robinson et al., 2001; Shaji et al., 2009).

Clinically, caregiver burden is not a diagnosable psychological condition in the current version of the *Diagnostic and Statistical Manual, 5<sup>th</sup> Edition (DSM-5; APA, 2013)* or under current ICD-10 diagnostic specifications. However, individuals experiencing high levels of caregiver burden are likely to experience varying levels of psychopathology. According to the Alzheimer's Association (2018), approximately 30-40% of family caregivers caring for



individuals with dementia suffer from elevated levels of depressive symptoms, compared to 5-17% of age-matched non-caregivers. Physical health also is known to suffer among caregivers with high levels of caregiver burden: 38% of dementia caregivers report elevated levels of physical stress, and 29% report high to very-high levels of physical strain related to caregiving tasks (Alzheimer's Association, 2018). Reidel and colleagues (2016) further reported that 73.7% of caregivers experiencing caregiver burnout may present with diagnosable characteristics of at least one somatic disorder, and 43.7% present with clinically relevant depressive symptoms – 37.5% of whom meet criteria for major depressive disorder.

Because caregiver burden itself is not a diagnosable condition, specific identifiable symptoms or “diagnostic criteria” often vary among the literature. Krishnan and colleagues (2017) operationalize caregiver burden as consisting of five primary components: (1) physical burden of care, which can include fatigue, exhaustion, and sleep disturbances; (2) psychological burden, which can include irritability, anger, depressive symptoms, difficulty concentrating, grief, and sadness; (3) social withdrawal and feelings of isolation; (4) loss of intimacy in ones relationships; and (5) financial burden, which can include loss of employment, increased financial strain of caregiving, and difficulty maintaining work responsibility. Marvardi and colleagues (2005) operationalized caregiver burden as being comprised of five primary constructs of burden, separate from those defined by Krisnan and colleagues (2017): (1) time dependent burden, which pertains to the overall amount of time a caregiver devotes to his or her care-recipient; (2) developmental burden, which includes aspects of social withdrawal and sense of dissatisfaction with one's current stance in their developmental life span; (3) physical burden, which includes sleep disturbances, physical health complications, and physical strain and fatigue; (4) social burden, which encompasses feelings of relational dissatisfaction and relational

problems and decreased self-efficacy in social/work scenarios; and (5) emotional burden, which includes feelings of embarrassment, resentment, and anger toward one's care-recipient (Marvardi et al., 2005). Truzzi and colleagues (2012) also describe a different characterization of caregiver burden. They describe caregiver burden as being comprised of three distinct dimensions: (1) emotional exhaustion, which refers to an overall lack of energy and depletion of one's emotional resources; (2) depersonalization, or cynicism, which is classified as the development of an impersonal attitude between one's self and the care-recipient; and (3) reduced personal accomplishment, which is described as the tendency to perceive or describe one's own work as negative or ineffective, both in and out of the context of providing care (Truzzi et al., 2012).

One potential explanation for the significant heterogeneity in the operationalizations of caregiver burden is the fact that caregiver burden can be experienced in the context of a multitude of care-recipient diagnoses. These can include, but are not limited to, dementia, stroke, traumatic brain injuries, cancer, and many more (Adelman et al., 2014), and each medical condition or disorder is likely to present with highly specific challenges for the caregiver. As a result, attempts to classify a single phenomenon experienced across caregivers of individuals with various different medical disorders have produced widely heterogeneous operational definitions of caregiver burden (Adelman et al., 2014). Regardless of how it is classified or operationalized, though, it is clear that caregiver burden is a multifaceted experience that is pervasive through multiple areas of a caregiver's life, not just within the context of providing care.

Due to the extreme heterogeneity in the operationalizations of caregiver burden from study-to-study, the prevalence rates of caregiver burden also vary across the body of empirical literature. One Australian longitudinal study following caregivers ( $n = 732$ ) of persons with

dementia over a 12-month period found that 57.7% of caregivers endorsed elevated levels of caregiver burden by the 12-month follow-up point (Brodaty et al., 2014). Another study of 200 primary caregivers partitioned experiences of caregiver burden by specific traits or symptomatic presentations: having little time for one's self (53%), worsening physical health or physical health complications (55%), fatigue (56%), sleep disturbances (51%), family and relational disturbances (55%), work- and occupational-related difficulties (57%), and self-reported sense of wishing to move away from home or remove themselves from their caregiving role (29%; Ferrara et al., 2008). A meta-analytic study forwent the classification of caregiver burden entirely and instead analyzed the prevalence of specific mental health concerns among primary caregivers ( $n = 10,825$ ) of persons with dementia, finding that approximately 34% of caregivers demonstrated clinically elevated levels of depressive symptoms, 43.6% demonstrated clinical elevations in anxious symptoms, and 27.2% exhibited problematic use of psychotropic drugs (Sallim et al., 2015). Yet another survey of 172 caregivers reported that approximately 68% of caregivers demonstrated significantly elevated levels of burden, with 65% of burdened respondents exhibiting elevated levels of depressive symptoms (Papastavrou et al., 2007). Regardless of how it is defined or operationalized, the experience of caregiver burden appears to be widespread, rather than isolated, and thus poses a significant concern and target for intervention.

Cultural factors may also play a role in caregivers' experiences of caregiver burden. One multinational systematic review of caregiver burden demonstrated that symptomatic experiences of caregiver burden were relatively similar across cultures, marked by increased rates of depressive and anxious symptoms, sleep disruptions, physiological health complications, and diminished social functioning (Torti et al., 2004). However, individual cultural factors may

impact the impact of caregiver burden and the severity of related experiences. Certain risk factors of caregiver burden were found to be relatively similar across North American, European, Australian, and Asiatic cultures: age of the caregiver, age of the care recipient, gender of the caregiver (women appear more at risk across cultures), perceived negative social reactions towards the caregiver, BPSDs, dementia severity, availability and use of community-based resources, and social/familial support. Even across North American studies, race/ethnicity was not found to be a significant predictor of one's experience of or severity of caregiver burden (Torti et al., 2004). The most notable difference in caregiver burden experiences across cultures concerns filial obligation – a perceived sense of responsibility and duty one feels towards family members (Torti et al., 2004). Studies of caregiver burden among Asiatic cultures found higher experiences of filial obligation to be a significant protective factor against experiences of caregiver burden (Chou et al., 1999; Lai, 2010; Lee & Sung, 1998; Torti et al., 2004), highlighting the potential split between individualistic and collectivistic cultural experiences of caregiver burden. While filial obligation as a protective factor is not exclusive to Asiatic or other collectivistic cultures, as this correlation was found across both individualistic and collectivistic cultural groups (Albert, 1990; Steins et al., 2006), it appears to be a more common experience among more collectivistic cultures (Chou et al., 1999; Lai, 2010; Lee & Sung, 1998; Steins et al., 2006; Torti et al., 2004).

Experiences of caregiver burden have been associated with higher rates of psychotropic drug use, physical and mental health problems, social isolation, family and relational stress, and depression (Camargos et al., 2012; Ostwald et al., 1999; Sallim et al., 2015). In the absence of adequate resources, these experiences, in conjunction with overall levels of caregiver burden, can inadvertently reduce the quality of care and adherence to medically informed care plans provided

by caregivers (Greenberger & Litwin, 2003). While it has been suggested that increased level of caregiver burden may increase the rate of the care-recipient becoming institutionalized (Lopez-Hartmann et al., 2012), other studies have shown that even in the face of high levels of caregiver burden, institutionalization is an unlikely outcome (Aneshensel et al., 1993). This could be due to a multitude of factors, including cultural dynamics and/or financial means, but it may also be due to a phenomenon labeled *role captivity*, which is defined as “the gradual absorption of a person into a caregiving role” (Aneshensel et al., 1993, p. 55). In addition to the role that the caregiver previously held in relation to his/her care-recipient (e.g., spouse, sibling, or child), they integrate into their sense of identity the role of caregiver as well, and the norms of adult autonomy are replaced with patient-dependency and role-related expectations (Aneshensel et al., 1993). As a result, institutionalization becomes an affront to one’s newfound integrated sense of identity, thus reducing the likelihood of transitioning care to external resources; however, this in-turn serves to further solidify and increase one’s experience of caregiver burden, as it may inadvertently instill a sense of helplessness and role-related strain (Aneshensel et al., 1993). Other studies have provided further empirical support for this hypothesis, as experiences of role captivity have been positively correlated with experiences of caregiver burden, with greater role captivity increasing levels of caregiver burden, and has even been identified as a predictor for depressive symptoms and caregiver burden ( $\beta = -0.38, p < .001$ ; Lawrence et al., 1998).

### **Treatments and Interventions Targeting Caregiver Burden in Dementia Caregivers**

When examining treatment methodologies for caregiver burden among primary caregivers of persons with dementia, a 2001 meta-analysis (24 studies) identified six potential categories of treatment modalities: (1) support groups, which provided a group-based setting for individuals to share their experiences and have them normalized by others; (2) education, which

is an intervention in which standardized information is provided about the disease progression and caregiving strategies to enhance the ability of the caregiver; (3) psychoeducation, which includes both education- and support-based strategies; (4) counseling, which is an individual treatment modality in which individual needs of the patient/participant are targeted to facilitate change in an individualized area of caregiving; (5) respite care, which is the inclusion of one or more additional caregivers to allow a break, or respite, for the primary caregiver in question; and (6) multi-component interventions, which are combinations of two or more areas of intervention to create a more comprehensive treatment program (Acton & Kang, 2001). It should be noted that by this definition, psychoeducational interventions do qualify as multi-component, as they include both education- and support-based interventions; however, due to the commonality of its use as a treatment approach, psychoeducational interventions are often included within single-component, rather than multi-component, interventions as (a) to ensure they receive their proper place within the empirical findings and (b) to not confound the analyses of more novel integrations of multiple treatment components or approaches (Acton & Kang, 2001).

Support groups have typically been found to demonstrate low-to-null effects in reducing caregiver burden across the literature (Acton & Kang, 2001; Chien et al., 2011; Chu et al., 2011; Lopez-Hartman et al., 2012; see Table 1). The duration of the support group has been shown to positively predict overall intervention effectiveness (Chien et al., 2011), and the use of a theoretical model to guide supportive interventions also increases effectiveness of the overall intervention (Chien et al., 2011). However, most groups appear to be fairly short in duration (e.g., less than 16 weeks; Chien et al., 2011), non-theoretically oriented (Acton & Kang, 2001), and many support groups meet infrequently (e.g., less than once/week) and allow participants to

join or leave the group as they please (Acton & Kang, 2001), thus preventing cohesive group dynamics to form (Yalom & Leszcz, 2005).

Education-based interventions also demonstrate mixed results in the literature (see Table 1 for available effect sizes). However, it is difficult to determine the exact effects of pure educational interventions on caregiver burden, as many education-based interventions also incorporate social support and supportive interventions, which thus classifies them as psychoeducational interventions (Acton & Kang, 2001). Specific studies that have examined solely education-based interventions for caregiver burden include methods such as providing self-help books, online and paper-based educational resources, physicians/clinicians providing verbal-based information on dementia and the disease progression, and home-based educational interventions (Gluckauf et al., 2004; Melis et al., 2009; Oken et al., 2010). While most of these interventions produce statistical improvements in observed BPSDs in the care-recipient and self-efficacy in seeking additional help/resources, minimal to null treatment effects were noted for addressing actual caregiver burden, stress, strain, or overall caregiver psychological wellbeing (Acton & Kang, 2001; Gluckauf et al., 2004; Melis et al., 2009; Oken et al., 2010).

Psychoeducation has also produced mixed results in improving caregiver burden (see Table 1 for available effect sizes). While some studies suggest that psychoeducational interventions reduce BPSDs in the care-recipient and negative caregiver reactions to BPSDs (Diehl et al., 2003), the overall effects of these interventions on objective measures of caregiver burden have again shown minimal to null treatment effects (Acton & Kang, 2001; Diehl et al., 2003; Ostwald et al., 1999). Overall, psychoeducational interventions appear to provide the most benefit in either (a) reducing observed BPSDs (Ostwald et al., 1999) or (b) increasing one's ability to cope with persisting BPSDs (Hepburn et al., 2005; Lopez-Hartman et al., 2012;

Ostwald et al., 1999; Toseland et al., 1992). However, the overall effectiveness of these interventions in reducing objective levels of caregiver burden is questionable at best.

While respite care can take many forms (e.g., in-home respite, adult day care, and residential care; Dementia Care Central, 2018), many appear to do little in reducing overall levels of caregiver burden (Mason et al., 2007; Oken et al., 2010; Vandepitte et al., 2016; see Table 1 for available effect sizes). While some studies report a reduction in depressive symptoms and anger towards the care-recipient (Mason et al., 2007; Shaw et al., 2009), these studies also report negative impacts (i.e., reductions) in overall perceived quality of life for the caregiver (Shaw et al., 2009). The flexibility of respite services also significantly impacts their abilities in reducing caregiver burden – services that are perceived as inflexible within the time- or funding-constraints of the caregiver are more likely to produce null changes in caregiver burden (Shanley, 2006). Additionally, the utilization of respite services has also been shown to accelerate the rate of hospitalization or permanent placement of the care-recipient into a long-term care facility – a trend which has remained constant over the last 20 years (Vandepitte et al., 2016; Zarit et al., 1999), negatively impacting the care-recipient's overall wellbeing by removing them from their preferred and familiar environment (Vandepitte et al., 2016).

Financial means of the caregiver have been identified as barriers to seeking respite services (Brodaty et al., 2005), and some cost-effectiveness analyses have shown that respite services are either just as expensive (Mason et al., 2007) or more expensive than providing at-home care by oneself (Pimouguet et al., 2010). The nationwide average cost for in-home respite care is approximately USD\$20/hour; adult day care costs approximately USD\$72/day; and residential respite care costs approximately USD\$125/day (Dementia Care Central, 2018). Given that most insurance plans do not cover all respite care-related costs, caregivers are forced to pay



for most services out of pocket (NIA, 2017), thus placing further financial strain and burden onto the caregiver.

The Resources for Enhancing Alzheimer's Caregiver Health II (REACH II) intervention program is a highly personalized, multi-component intervention targeting the reduction of caregiver burden among at-home caregivers of persons with dementia. The program includes at-home visits by trained staff to assess individual areas of need for care and to provide in-the-moment care-based interventions, online educational material, telehealth interventions, comprehensive and individualized risk assessment, and an individualized care plan for the reduction of caregiver burden (USDHHS, 2003). The REACH II program has garnered significant empirical support, demonstrating efficacy in reducing caregiver burden compared to other treatment interventions and no-treatment controls; however, effect sizes tend to be in the mild or mild-to-moderate ranges (Altpeter et al., 2013; Belle et al., 2006; Burgio et al., 2009; Gitlin et al., 2003; Nichols et al., 2008; Nicols et al., 2011; see Table 1 for available effect sizes). One cost-effectiveness analysis of the REACH II program reported that the overall cost of the program per caregiver was approximately USD\$1,214. However, while significant reductions in the amount of time per day spent caregiving were noted, these reductions only equated to USD\$893 saved over the course of a six-month intervention period (Nichols et al., 2008). As a result, the cost output exceeds the potential money (or monetary equivalent) saved by the caregiver within the scope of the intervention. Current studies also do not demonstrate adequate follow-up data to determine if the treatment effects and time-saved persists post-treatment (Nichols et al., 2008), so the overall cost-effectiveness over time of the REACH II program via maintenance of relevant treatment/financial gains is unclear.

Individual psychotherapy/counseling has also been utilized for the reduction of caregiver burden among primary family caregivers of persons with dementia and have been shown to be effective (Gaugler et al., 2008; Pinquart & Sörensen, 2006; see Table 1 for available effect sizes). Most individual psychotherapeutic interventions tend to blend supportive interactions, educational information, and BPSD-focused coping skills within a theoretically oriented framework (Acton & Kang, 2001; Gaugler et al., 2008). Individual CBT for caregivers has been shown to produce significant reductions in levels of caregiver burden, physical strain, depressive symptoms, and reactions to BPSDs with strong effect sizes sustained up to three-month follow-up (Secker & Brown, 2004; Yoo et al., 2019; see Table 1 for available effect sizes).

Group-based therapies have also shown to be a highly effective modality of intervention, and they allow for the intervention to be provided to multiple people at a time rather than a single individual (Yalom & Leszcz, 2005). DBT skills-based group interventions have shown some effect at reducing overall burden levels and depressive symptoms while improving physiological health outcomes among caregivers (Drossel et al., 2011). CBT group therapy was also found to produce significant reductions in caregiver burden scores (Secker & Brown, 2004) as well as significant reductions in salivary cortisol levels – a biophysiological measure of stress (Abdoulafia-Brakha et al., 2014). For specific group therapy effect sizes, see Table 1 below.

While group therapy is typically administered in-person, online or technology-based group therapies have also shown some positive results for reducing depressive symptoms among caregivers of persons with dementia; however, the results across studies tend to be mixed (Scott et al., 2016; see Table 1 for specific effect sizes). When examining online group therapies, online social support groups have shown some mild effects in improving self-efficacy and caregiver stress (Marziali & Garcia, 2011; Pagán-Ortiz et al., 2014); however, synchronous and face-to-

face online groups tend to provide greater treatment effects than asynchronous chatroom-style online groups (Marziali & Garcia, 2011). Few technology-based group therapeutic studies have implemented adequate post-treatment follow-up measures, so the sustainability of their treatment gains may be questionable compared to in-person groups (Scott et al., 2016). For effect sizes of technology-based group therapies, see Table 1.

Table 1

Systematic Review of Existing Treatments for Caregiver Burden in Primary Family Caregivers of Persons with Dementia

Study	Sample Size	Intervention(s)	Outcome Variable (Measure)	Effect Size(s)
Burgio et al., 2009	<i>N</i> = 236	REACH II	Caregiver Burden (ZBI)	<i>d</i> = 0.25*
			Depression (REACH-II-RA-D)	<i>d</i> = 0.22*
			Social Support (REACH-II-RA-SS)	<i>d</i> = -0.30*
			Positive Aspects of Caregiving (REACH-II-RA-P)	<i>d</i> = -0.23*
			ADL Stress (REACH-II-RA-ADL)	<i>d</i> = 0.12
			Behavioral Bother (REACH-II-RA-BB)	<i>d</i> = 0.13
			Frustration (REACH-II-RA-F)	<i>d</i> = 0.33*
Gitlin et al., 2003	<i>N</i> = 910	REACH II	Caregiver Burden (RMBPC-B)	<i>d</i> = 0.32*
			Depression (CES-D)	<i>d</i> = 0.13*
Nicols et al., 2011	<i>N</i> = 105	Online REACH-II	Caregiver Burden (ZBI)	<i>d</i> = 0.33*
			Depression (PHQ-9)	<i>d</i> = 0.26*
			BPSDs (REACH-II-RA)	<i>d</i> = 0.20*
			Frustration (REACH-II-RA-F)	<i>d</i> = 0.30*
			Health Behaviors (REACH-II-RA-HB)	<i>d</i> = 0.10
			Safety (REACH-II-RA-S)	<i>d</i> = 0.04
			Social Support (REACH-II-RA-SS)	<i>d</i> = 0.06
			BPSD-specific burden and bother (REACH-II-RA-BB)	<i>d</i> = 0.03

			General Health (MOS-36)	$d = 0.11$
			Time Spent Caregiving (hours)	$d = 0.15$
Acton & Kang, 2001	$N = 24$ studies (meta-analysis)	Support Groups	Caregiver Burden (ZBI, MBBS, CBI)	$d = 0.00$
Chu et al., 2011	$N = 60$	Support Groups	Caregiver Burden (CBI)	$d = 0.06$
			Depression (BDI-II)	$d = -0.16$
Chien et al., 2011	$N = 30$ studies (meta-analysis)	Support Groups	Global mental health concerns: Anxiety, anger/hostility, depression ( <i>mns</i> )	$g = -0.44^*$
			Caregiver Burden ( <i>mns</i> )	$g = 0.23^*$
Acton & Kang, 2001	$N = 24$ studies (meta-analysis)	Education	Caregiver Burden (ZBI, MBBS, CBI)	$d = -0.52^*$
Oken et al., 2010	$N = 31$	Education	BPSDs (RMBPC)	$d = 1.04^*$
			Overall stress (PSS)	$d = -0.40$
			Stress (Salivary Cortisol)	$d = 0.28$
			Depression (CES-D)	$d = 0.27$
			Fatigue (SF-36)	$d = 0.17$
			Self-Efficacy (GPSE)	$d = -0.06$
			Sleep Quality (PSQI)	$d = 0.00$
Glueckauf et al., 2009	$N = 21$	Education	Efficacy in Caring for Respite Needs (CSES-SEOR)	$d = -0.83^*$
			Managing BPSDs (CSES-RDPB)	$d = -0.89^*$
			Cognitive Coping (CSES-CUTC)	$d = -0.75^*$
			Overall Subjective Emotional Burden (CAI-SEB)	$d = 0.69^*$
			Positive Attitudes towards Caregiving (CAI-PA)	$d = -0.48$
			Time-Dependent Burden (CAI-TB)	$d = 0.35$
			Overall Stress (SRG)	$d = 0.35$
Melis et al., 2009	$N = 84$	Education	Caregiver Burden (ZBI)	$d = -0.09$
Acton & Kang, 2001	$N = 24$ studies (meta-analysis)	Psychoeducation	Caregiver Burden (ZBI, MBBS, CBI)	$d = -0.06$
Ostwald et al., 1999	$N = 94$	Psychoeducation	Caregiver Burden (ZBI)	$d = 0.23^*$
			Depression (CDS-D)	$d = 0.10$
			Response to BPSDs (RMBPC-R)	$d = 0.67^*$
Hepburn et al., 2005	$N = 166$	Psychoeducation	Caregiver Burden (ZBI)	$d = -0.15$
			Stress ( <i>mns</i> )	$d = -0.09$
			Perceived Caregiving Competence	$d = -0.45^*$

			( <i>mns</i> )	
			Relational Deprivation ( <i>mns</i> )	$d = -0.38^*$
			Role Captivity ( <i>mns</i> )	$d = -0.19$
			Beliefs About Caregiving (BACS)	$d = 0.08$
Acton & Kang, 2001	$N = 24$ studies (meta-analysis)	Respite Care	Caregiver Burden (ZBI, MBBS, CBI)	$d = -0.02$
Oken et al., 2010	$N = 31$	Respite Care	BPSDs (RMBPC)	$d = -0.10$
			Overall stress (PSS)	$d = -0.14$
			Stress (Salivary Cortisol)	$d = 0.00$
			Depression (CES-D)	$d = -0.15$
			Fatigue (SF-36-E/F)	$d = -0.16$
			Self-Efficacy (GPSE)	$d = -0.33$
			Sleep Quality (PSQI)	$d = 0.07$
Shaw et al., 2009	$N = 104$ (meta-analysis)	Respite Care	Caregiver Burden ( <i>mns</i> )	$d = -0.58^*$
Mason et al., 2007	$N = 22$ studies (meta-analysis)	Respite Care	Caregiver Burden (ZBI, CBI, CSI, CIQ, ROS)	$d = -0.03$
			Depression (HAM-D, GDS, CES-D)	$d = -0.32^{*\dagger}$
Acton & Kang, 2001	$N = 24$ studies (meta-analysis)	Individual Counseling	Caregiver Burden (ZBI, MBBS, CBI)	$d = -0.07$
Pinquart & Sörensen, 2006	$N = 13$ studies (meta-analysis)	Individual Counseling (non specific)	Caregiver Burden ( <i>mns</i> )	$ES_{adj} = -0.50^*$
Pinquart & Sörensen, 2006	$N = 13$ studies (meta-analysis)	Individual Counseling (CBT)	Caregiver Burden ( <i>mns</i> )	$ES_{adj} = -0.36^*$
Secker & Brown, 2004	$N = 30$	Individual Counseling (CBT)	Caregiver Burden (CBI)	$d = 2.95^*$
			Caregiver Strain (CSI)	$d = 1.90^*$
			Psychological Health (GHQ)	$d = -0.57^*$
			Somatic Symptoms (GHQ-SS)	$d = 1.18^*$
			Anxiety and Insomnia (GHQ-AI)	$d = 3.41^*$
			Social Dysfunction (GHQ-SD)	$d = 2.74^*$
			Depression (GDS-SF)	$d = 1.34^*$
Yoo et al., 2019	$N = 38$	Individual Counseling (CBT)	Caregiver Burden (ZBI)	$d = 0.60^*$
			Depression (GDS)	$d = 0.49^*$
			Positive Affect (PANAS-PA)	$d = -0.08$
			Negative Affect (PANAS-NA)	$d = -0.18$

			Self-Compassion (SCS)	$d = -0.09$
			Behavioral Effectiveness (AAQ-II)	$d = -0.03$
			Caregiver Neuropsychiatric Symptoms (CGA-NPI)	$d = -0.02$
Drossel et al., 2011	$N = 16$	Group Counseling (DBT Skills)	Caregiver Burden (CBI)	$d = 0.32^*$
			Depression (CES-D)	$d = 0.50^*$
			Role Limitations (SF-36-RLE)	$d = -0.50^*$
			Fatigue (SF-36-E/F)	$d = -0.33^*$
			Emotional Wellbeing (SF-36-EW)	$d = -0.45^*$
			Social Functioning (SF-36-SF)	$d = -0.45^*$
Aboulaflia-Brakha et al., 2014	$N = 12$	Group Counseling (CBT)	Stress (Salivary Cortisol)	$\eta_p^2 = 0.67^*$
Scott et al., 2016	$N = 4$ studies (meta-analysis)	Group Counseling (TB-CBT)	Depression (CES-D)	$d = -0.15 - -0.20$
			Depression (BDI-SF)	$d = -1.30^*$
McDermut et al., 2001	$N = 48$ studies (meta-analysis)	Group Counseling (CBT)	Depression (BDI-II)	$d = 1.03^*$
Thimm & Antonsen, 2014	$N = 143$	Group Counseling (CBT)	Depression (BDI-II)	$d = 0.97-1.10^*$
Marziali & Garcia, 2011	$N = 40$	Online Support Group, Chat-Room Only	Mental Health Status (HSQ-m)	$d = 0.18^*$
			Caregiver Distress (SMAF)	$d = 0.04^*$
Marziali & Garcia, 2011	$N = 51$	Online Support Group, Video Face-to-Face	Mental Health Status (HSQ-m)	$d = 0.26^*$
			Caregiver Distress (SMAF)	$d = 0.30^*$
Pagán-Ortiz et al., 2014)	$N = 17$	Online Support Group	Perceived Mastery and Competence in Providing Care (PMS)	$d = -0.24$
			Perceived Social Support (LSNS)	$d = 0.12$
			Caregiver Burden (ZBI)	$d = -0.18$
			Depression (CES-D)	$d = -0.05$
Kwok et al., 2014	$N = 36$	Online Individual Therapy (CBT)	BPSD Severity (CGA-NPI)	$d = 1.01^*$
			Caregiver Distress (CGA-NPI-s)	$d = 0.66^*$
			Self-Efficacy in Responding to Disturbing Behaviors (CSE-RDB)	$d = -0.47$
			Self-Efficacy in Controlling Upsetting Behaviors (CSD-CUT)	$d = -0.61$

Acton & Kang, 2001	<i>N</i> = 24 studies (meta-analyses)	Other Multi-Component Interventions	Caregiver Burden (ZBI, MBBS, CBI)	<i>d</i> = 0.46*
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\* denotes statistical significance, with  $p < 0.05$

†Authors report that while this effect size was statistically significant, it was likely confounded by the inclusion of one study in the meta-analysis which met inclusion criteria but was also characterized by confounding methodology. When this single study was removed from the analyses, the effect size was reduced and no longer significant (reduced effect size not reported (Mason et al., 2007).

*d* = Cohen's *d* effect size; *g* = Hedge's *g* effect size; *ES<sub>adj</sub>* = Adjusted effect size; *mns* = measure not specified; CBT = Cognitive Behavioral Therapy; TB-CBT = Technology-Based CBT; ZBI = Zarit Burden Interview; MBBS = Montgomery-Borgatta Burden Scale; CBI = Caregiver Burden Inventory; CES-D = Center for Epidemiologic Studies Depression Scale; MOS-36 = Medical Outcomes Study Short-Form 36; REACH II = Resources for Enhancing Alzheimer's Caregiver Health II Intervention Program; REACH-II-RA = Resources for Enhancing Alzheimer's Caregiver Health II Assessment for Risk Appraisal (D = depression subscale, SS = social support subscale, P = positive aspects of caregiving subscale; ADL = stress related to activities of daily living subscale, BB = behavioral bother subscale, F = frustration subscale; HB = health behaviors subscale; S = safety subscale); RMBPC = Revised Memory and Behavioral Problems Checklist (B = burden subscale, R = caregiver response subscale); BDI-II = Beck Depression Inventory, second edition; PCS = Preparedness for Caregiving Scale; GHQ = General Health Questionnaire; GDS = Geriatric Depression Scale, GCS = General Contentment Scale, HDLF = Health and Daily Living Form); BPSDs = Behavioral and Psychological Symptoms of Dementia; PSS = Perceived Stress Scale; SF-36 = Physiological Health Questionnaire (RLE = role limitations due to emotional difficulties subscale, E/F = energy and fatigue subscale, EW = emotional wellbeing subscale, SF = social functioning subscale); GPSE = General Perceived Self-Efficacy Scale; PSQI = Pittsburgh Sleep Quality Index; CSES = Caregiving self-efficacy scale (SEOR = caring for respite needs subscale, RDPB = managing disruptive and challenging behaviors subscale, CUTC = response to cognitions subscale); CAI = Caregiver Appraisal Inventory (SEB = subjective emotional burden subscale, PA = positive aspects of caregiving subscale, TB = time burden subscale); SRG = Stress Related Growth Scale; BACS = Beliefs About Caregiving Scale; CSI = Caregiver Strain Index; CIQ = Caregiver Impact Questionnaire; ROS = Role Overload Scale; HAM-D = Hamilton Depression Scale; GHQ = General Health Questionnaire (SS = somatic symptoms subscale, AI = anxiety and insomnia subscale, SD = social dysfunction social scale); GDS-SF = Geriatric Depression Scale, Short Form; PANAS = Positive and Negative Affect Schedule (PA = positive affect subscale, NA = negative affect subscale); SCS = Self-Compassion Scale; CGA-NPI = Caregiver Administered Neuropsychiatric Inventory (s = stress subscale); WoC-R = Ways of Coping Checklist, Revised (SS = social support subscale, SB = self-blame subscale, WT = wishful thinking subscale, AV = avoidance subscale, PF = problem-focused coping subscale); MBI = Maslach Burnout Inventory (EX = emotional exhaustion subscale, Dep = depersonalization and objectification subscale); STAI = State-Trait Anxiety Inventory (S = state anxiety subscale, T = trait anxiety subscale); BDI-SF = Beck Depression Inventory, Short Form; HSQ = Health Status Questionnaire (m = mental health status subscale); SMAF = Functional Autonomy Measurement System; CSE = Caregiving Self-

Efficacy Scale, Revised (RDB = disturbing behaviors subscale; CUT = ability to control upsetting thoughts subscale)

### **Considerations for Online Group Therapies**

As societal technology has advanced, psychotherapeutic techniques have advanced alongside it. One of the most remarkable technological advancements of our time is undoubtedly the advent of the internet, allowing a wide-scale platform for free expression, bringing external reality closer, and enhancing communication between parties (Machado et al., 2016). Online and tele-based therapies have provided alternative and, at times, more accessible modalities of treatment due to increased flexibility and reduced constraints (Machado et al., 2016). Online therapies have the opportunity to circumnavigate many barriers to traditional treatments, including restrictions pertaining to hours of operations, mobility challenges, transportation-related difficulties, and medical and other disabilities which may prevent one from attending regular in-person psychotherapy appointments (Harris & Birnbaum, 2015).

Online therapy practices have been explored since the late 1990s; these practices have gone by many names, including e-therapy, cybertherapy, webcounseling, and simply online psychotherapy (Chester & Glass, 2006). Online psychotherapeutic resources that are available range from online self-help software packages such as downloadable self-help applications to actual direct contact between a patient and a therapist via internet. Direct communications between a patient and a therapist online can take a few different forms, including private chatroom-like forums and face-to-face video conferencing (Chester & Glass, 2006). In addition, online based therapies have been used as both stand-alone interventions as well as adjunctive treatments alongside more traditional in-person therapy (Harris & Birnbaum, 2015). However,



despite its advantages, certain issues of online communications for psychotherapeutic practices brings about their own ethical concerns that must be considered.

### ***Ethical and Legal Concerns of Online Psychotherapy***

Even though online therapeutic formats may increase accessibility for some, the new concern becomes reliable access to internet technologies and the ability to use these technologies which some individuals, groups, or populations may not have. As a result, concerns surrounding the exclusionary nature of online psychotherapies have arisen, as they may create an environment which limits accessibility only to the technologically literate (Harris & Birnbaum, 2015). While certain online formats may allow for increased anonymity, an issue might arise when anonymity is taken too far. Online environments have been found to encourage role-play and the creation of almost new identities which individuals may assume only in online formats (Gwinnell, 2003). This issue is not limited solely to the patients/clients, as therapists and counsellors may also be prone to self-misrepresentation online (Harris & Birnbaum, 2015). Because of potential concerns surrounding identity and anonymity of the patients/clients, the ethical use and appropriateness of online therapeutic modalities in the context of severe mental health concerns has been questioned (Harris & Birnbaum, 2015).

Asynchronous communication can also become an issue, as lapses in time between online communications (especially in e-mail and chatroom-based formats) may impede immediacy, genuineness, and therapeutic relationship – all of which are key factors in effective therapeutic processes (Harris & Birnbaum, 2015). By extension, emergency communications also warrant discussion. Asynchronous communication may produce lags in response times which, during emergencies and patient-/client-safety concerns, may prove costly. However, more synchronous e-communication methods such as tele- and text-based communications may have diminished

genuineness and empathy compared to face-to-face communications, and they also create situations in which the ethical boundaries of the therapist become difficult to maintain (Harris & Birnbaum, 2015). In addition, the lack of non-verbal information creates situations rife for miscommunications, misunderstandings, and misconceptions as well as increased emotional distance between the patient and the therapist which may impede the development of or rupture an existing therapeutic relationship (Harris & Birnbaum, 2015).

Another major concern for the ethical use of online technology is of course the protection of patient confidentiality and the security of patient information. With the increase of online technologies and communications also comes the increased risk of cybercrime, cyberattacks, and breaches of personal information via online formats. As technology has advanced over the last few decades, cyberattacks and online breaches of personal information have also increased (Song et al., 2015). Given therapists' ethical duties to protect patient confidentiality and information, this is arguably one of, if not, the most significant concern for online psychotherapy practices. Frequent technological upgrades are required on both the therapist's and the patient's ends to decrease the risk of these information and security breaches. Despite efforts to reduce the risk of these cyberbreaches, the possibility is never eliminated entirely, thus warranting continual consideration (Harris & Birnbaum, 2015). It is the therapist's ethical responsibility to protect the patient's information as well as ensure that the patient is informed of the potential risks via proper informed consent.

Informed consent provides the final major ethical and legal consideration for online therapists. Due to the aforementioned concerns of falsified/altered identity, asynchronous communication, lack of non-verbal cues, risk of miscommunications, diminished emotional closeness and genuineness, and lack of technological literacy, providing proper informed consent

can become a challenge in online formats. The therapist must ensure that the patient is truly informed of the procedures and potential risks of online psychotherapy without coercion in any way (Harris & Birnbaum, 2015). Depending on the modality of online communication, it can be difficult to ensure that every patient has the ability and opportunity to ask any/all questions pertaining to the consent form(s). Additionally, a patient's capacity for providing informed consent can also be misjudged or misconstrued, as this can be more difficult to accurately assess in online formats compared to face-to-face communications (Harris & Birnbaum, 2015).

### ***Online Therapy Compared to In-Person Therapies***

Online psychotherapy has been explored in a wide variety of contexts and disorders, including insomnia, eating disorders, social anxiety disorder, depression, anxiety, and more. Historically, specific comparisons between traditional, in-person psychotherapeutic techniques and online psychotherapy have been difficult to make due to a wide range of methodological differences across online formats; however, as online and tele-based psychotherapies have received greater attention over the last decade, more evidence has been produced to support their efficacy (Egan et al., 2018). Recent studies have demonstrated that effect sizes for online psychotherapeutic treatment across a variety of psychological disorders, including those previously mentioned above, when compared to traditional in-person psychotherapeutic treatment have been markedly similar, demonstrating comparative efficacy in a variety of contexts (Anderson et al., 2016; Bruin et al., 2015; Ellis et al., 2011; Morland et al., 2015; Segal & Walsh, 2016; Zerwas et al., 2016).

### ***Group Processes in Online Group Therapies: The Online Group Climate***

Arguably the most important environmental process in group therapy is group cohesion, a social process that occurs within a group whose members are able to form relationships and

interact openly and meaningfully with one another and who feel a sense of togetherness (Yalom & Leszcz, 2005). With a cohesive group environment comes increased willingness and openness for free expression, increased group-based support, increased willingness to discuss potentially difficult or emotionally-charged topics which allows for emotional deepening within the group and for more effective and targeted interventions, and acceptance of others in a group-based format which ultimately allows for the eventual acceptance of one's self (Yalom & Leszcz, 2005). Group cohesion is ultimately the group process through which all other group processes flow (Yalom & Leszcz, 2005). With respect to online-based group therapies, group cohesion remains a key process of the group climate. Group cohesion significantly predicts effects of both in-person and online group therapeutic interventions across a variety of diagnostic contexts (Bauer et al., 2012; Ellis et al., 2014; May et al., 2004; Webber et al., 2008). Additionally, online group therapeutic modalities have been shown to produce high levels of group cohesion similar to those seen in in-person group therapies (Lin et al., 2018; McGill et al., 2017; Tate et al., 2017; Trachtenberg et al., 2019).

Social support as a group process also provides an important resource for people experiencing high levels of stress or experiencing stressful life adjustments (Mallinckrodt, 1989). Mutually exchanged social support can act as a powerful factor in bringing people together who have experienced similar traumas, transitions, or other stressful situations (Mallinckrodt, 1989). Group-based interventions are optimal treatment modalities for fostering and increasing social support (Cassie & Sanders, 2008; Pinguat & Sörrensen, 2006; Yalom & Leszcz, 2005), which is seen by patients as one of the most effective factor and process within their therapeutic experiences (Yalom & Leszcz, 2005). A vast body of literature supports the importance of social support within group therapy as a predictor of treatment-related outcomes in a variety of

therapeutic contexts (Beckner et al., 2010; Dadds & McHugh, 1992; Mallinckrodt, 1989; Röhrle & Strouse, 2008; Steketee, 1993; Thrasher et al., 2010; Yalom & Leszcz, 2005), especially when that social support is provided by peers who are experiencing similar circumstances to oneself (Mallinckrodt, 1989; Yalom & Leszcz, 2005).

With respect to online therapeutic modalities, studies have shown that social support remains an important factor in the overall outcomes of interest. Studies examining online group therapy formats have found high levels of perceived social support among group members across different diagnostic contexts (Ellis et al., 2011; Evans et al., 2012), and these levels of social support are similar to those noted in in-person group therapeutic formats (Berger, 2017; Colón & Stern, 2011; Coock & Doyle, 2002).

Another important process in the group therapy climate is the working therapeutic alliance (or just therapeutic alliance), which is defined as the relationship between the individual patient and the therapist/clinician (Yalom & Leszcz, 2005). Across the group therapy literature, working alliance and group cohesion are often categorized together; however, they represent two distinct constructs, with working alliance representing patient-to-therapist relationships and group cohesion representing patient-to-patient relationships within the group (Crowe & Grenyer, 2008). As a separate construct, working alliance can be assessed and characterized through the alignment of therapist and patient treatment goals, mutual trust in each other, mutual perceived involvement/engagement with the group process, and openness and honesty between the therapist and the patient (Crowe & Grenyer, 2008). In group therapy, the working alliance between the therapist and the individual patient is arguably as important of a process as overall group cohesion in providing an avenue through which therapeutic effects may be delivered (Crowe & Grenyer, 2008; Yalom & Leszcz, 2005). This relationship seems to remain true among

the online group therapy literature, in that a strong and positive therapeutic relationship is both possible and is significantly related to the overall treatment effects (McGill et al., 2017).

The final group process worth discussing is engagement. Engagement is sometimes referred to as attraction or attitude within the literature, and they have very similar operational definitions. Engagement, attraction, and attitude are often defined as one's desire to identify with and be an active member in his or her group (Evans & Jarvis, 1986; Yalom & Leszcz, 2005). It should be noted that attraction and attitude often get equated with cohesion (Chen & Mallinckordt, 2002); however, they are more closely associated with the process of engagement (Evans & Jarvis, 1986; Yalom & Leszcz, 2005). Engagement has been shown to significantly predict overall group therapeutic outcomes (Evans & Jarvis, 1986), with stronger engagement towards the group leading to stronger and more positive therapeutic outcomes. With greater levels of engagement comes greater group-wide participation, greater group cohesion, greater engagement with therapeutic activities outside of group, and more open and active communication within the group context (Evans & Jarvis, 1986; Yalom & Leszcz, 2005). With respect to online group therapy, a large concern within the body of research is how to optimize engagement within the online group context (Lederman et al., 2019). Despite this, online group therapies – especially more synchronous online modalities – have been shown to produce positive and stable levels of engagement in participants throughout the course of treatment (Gainsbury & Blaszczynski, 2011; Lederman et al., 2019; McGill et al., 2017).

When examining online group therapies and their ability to foster these critical group-wide processes, the media richness theory (MRT; Daft & Lengel, 1986) and the theory of media naturalness (TMN; Kock, 2004) combine to state that group processes in online communication formats are optimized when communication between group members takes place in a stimulus-

rich medium which emulates natural human communication to maximize social presence. Face-to-face, in-person group sessions would obviously create the most stimulus-rich environment and the most social presence, as people are able to meet in the same room and be together, thus providing natural human communication and fostering human connectedness in a natural and familiar manner. Online group therapies can fall along a spectrum of these characteristics: chatroom-like forums would be much lower on the spectrums of richness and naturalness, while technology-mediated face-to-face (i.e., teleconference platforms using webcams to allow face-to-face interaction over the internet) would be significantly higher along these spectrums (Lewandowski et al., 2011). As a result, online group therapeutic interventions which incorporate online-mediated face-to-face communication would produce the greatest levels of group cohesion, social support, working alliance, and engagement among group members out of the various online-mediated therapeutic techniques, thus maximizing the effectiveness of the online intervention (Lewandowski et al., 2011).

### ***Online Therapies for Caregiver Burden***

The current body of literature provides some support for the efficacy of online therapies in the reduction of caregiver burden and related comorbidities. In a study of online individual CBT treatment, results showed significant reductions in perceived BPSD severity and caregiver distress ( $d = 1.01$  and  $0.66$  respectively); however, no significant results were found in improving caregiver self-efficacy in responding to or controlling upsetting behaviors from the care-recipient (Kwok et al., 2014). When comparing online chatroom groups to technology mediated face-to-face groups, Marzaili and Garcia (2011) found that while both the online face-to-face groups produced significant improvements in self-efficacy and social supports and significant reductions in neuroticism and overall levels of caregiver stress, the online face-to-face

group produced significantly greater improvements in overall mental health status ( $d = 0.26$  vs.  $d = 0.18$ ) and greater reductions in overall caregiver-related stress ( $d = 0.30$  vs.  $d = 0.04$ ; Marziali & Garcia, 2011). However, another study investigating the efficacy of online support-only group interventions (online modality unclear) found non-significant effects on perceived self-efficacy in the caregiver role ( $d = -0.24$ ), perceived social support ( $d = 0.12$ ), overall levels of caregiver burden ( $d = -0.18$ ), and depressive symptoms ( $d = -0.05$ ; Pagán-Ortiz et al., 2014).

Consistent with these findings, meta-analytic review studies have found that online support-only groups tend to produce mixed or modest results across the body of literature (Lee, 2015, Egan et al., 2018). While this could be due to the variety of online therapeutic methodologies implemented, making comparisons difficult (Egan et al., 2018), it could also be due to the fact that supportive group interventions provide single-component interventions, thus reducing the likelihood that they will create impactful changes in overarching constructs such as caregiver burden (Acton & Kang, 2001). As a result, much like for in-person therapies, online therapies targeting caregiver burden should include multiple components to increase the intervention efficacy and patient outcomes.

### **Cognitive Behavioral Therapy (CBT)**

Cognitive Behavioral Therapy, or CBT, was founded by psychiatrist Dr. Aaron Beck in the 1960's. While he was trained in psychoanalysis, Dr. Beck, through a series of experiments, found that patients with depressive symptoms experienced streams of spontaneous negative thoughts, which he referred to as automatic thoughts (Beck Institute, n.d.). All automatic thoughts (positive or negative) were believed to ultimately stem from what Beck referred to as core beliefs – beliefs which individuals hold innately true, which are typically rooted deep within our unconscious minds, and which are highly resistant to change (Beck, 2011). Core beliefs can



arise from childhood experiences, major life stressors (e.g., traumas), innate dispositions, and cultural influences. Beck identified three primary categories for core beliefs: (1) beliefs about the self, (2) beliefs about others, and (3) beliefs about the world (Beck, 2011). Between automatic thoughts and core beliefs is an intermediary level of cognitive processing: intermediate beliefs or intermediate assumptions – attitudes or rules that a person holds within themselves which guide thoughts and behaviors and which apply across all situations (whereas automatic thoughts are highly situation-specific; Beck, 2011; Cully & Teten, 2008). To summarize, people inherently develop core beliefs, which promote the development of intermediate beliefs/assumptions, which in turn guide the development of automatic thoughts.

With this realization, Beck began to orient therapeutic treatment to identifying, evaluating, and challenging these automatic thoughts, intermediate assumptions/beliefs, and ultimately core beliefs. By doing so, his patients were able to think more positively and realistically, rather than being caught in a torrent of negative thoughts, thus improving their emotional well-being and behavioral functionality (Beck, 2011; Beck Institute, n.d.).

CBT is a goal-oriented, time-sensitive, educative, and collaborative modality of treatment (Beck, 1991; Beck, 2011). Its foundations were based on two primary theories of cognition and learning: (1) information-processing theory and (2) social learning theory (Beck, 1991; Beck, 2011; Cully & Teten, 2008). The information-processing theory of human cognition equates the human mind to a machine/computer – the mind receives input via the senses, processes said input, and creates/delivers output based on the input and how it was processed. How a message is processed in the mind is based on prior schemas – internalized representations or expectations of a given situation typically based on past experiences (Axelrod, 1973). When a maladaptive, faulty, or negative schema is evoked in a situation, the input is processed in a negatively biased

manner, thus resulting in negative automatic thoughts, which in turn lead to negative emotionality and maladaptive behavioral responses (Axelrod, 1973; Beck, 1991; Beck & Clark, 1997; Beck, 2011). While Beck (1991) originally used the information-processing model to conceptualize depressive symptoms, it has since been adapted to many other forms of psychopathology, including anxiety disorders (Beck & Clark, 1997) and many others (Beck, 2011).

Social learning theory is a theory typically applied to learning and behavior and was founded by Albert Bandura. According to Bandura, social learning theory states that people learn via observation, imitation, and modeling. Additionally, learning is highly consequence-dependent, meaning people are likely to learn and habituate certain behaviors that are rewarded, while behaviors with negative consequences are likely to dissipate from the individual's behavioral lexicon (Bandura & Walters, 1977). Social learning theory rests on four principal tenants: (1) attention to a given behavior being observed, (2) retention or remembering of the observed behavior, (3) reproduction of the observed behavior, and (4) motivation to reproduce the observed behavior (Bandura & Walters, 1977). When applying this information to the CBT framework discussed above, people are likely to learn maladaptive behavioral patterns from those around them. Additionally, core beliefs are likely to guide one's attention and retention of certain observable behaviors, thus influencing the reproduction and motivation to reproduce said behaviors as well (Cully & Teten, 2008). In addition, maladaptive behaviors become rewarded (either internally or externally) when they are in-line with a [maladaptive] core belief, thus further instilling the behavioral pattern within the psychopathological presentation (Beck, 2011; Cully & Teten, 2008).

The integration of Beck's framework of core beliefs, intermediate assumptions, and automatic thoughts with information-processing theory and social learning theory produce what is commonly referred to as cognitive-behavioral theory (Beck, 2011). It is important to note that the term cognitive-behavioral theory is a slight misnomer, as there is no true definition for a single, unified cognitive-behavioral theory which underlines CBT. Instead, cognitive-behavioral theory is a categorical term given to theories which value both the cognitive and the behavioral importance in the development and maintenance of psychopathology (Kalodner, 2011)

While CBT was originally developed to treat depressive disorders, it has grown to become one of the most widespread methodologies of psychotherapy. Beck (2011) outlines a list of psychiatric disorders, psychological problems, and medical problems with psychological components for which CBT has demonstrated significant empirical support in providing efficacious treatment: major depressive disorder, geriatric depression, generalized anxiety disorder, geriatric anxiety, panic disorder, agoraphobia, social phobia, obsessive-compulsive disorder, conduct disorder, substance abuse, attention-deficit/hyperactivity disorder, health anxiety, body dysmorphic disorder, eating disorders, personality disorders, sex offending, habit disorders, bipolar disorders (with medication), schizophrenia (with medication), couple problems, family problems, pathological gambling, complicated grief, caregiver distress (i.e., caregiver burden), anger and hostility, chronic pain related to a medical condition, chronic fatigue, insomnia, obesity, hypertension, and more (Beck, 2011, p. 4).

Naturalistic research studies have shown over time that group-based and individually delivered CBT both produce significant treatment effects (Kellet et al., 2007; Peterson & Halstead, 1997; Westbrook & Kirk, 2005). Both group-based and individual CBT demonstrate effectiveness at treating depressive disorders, even in the presence of high comorbidity; however,

individual CBT was found to produce larger effect sizes than group-based CBT on depressive symptoms as measured by the BDI-II ( $d = 1.30$  and  $d = 0.93$  respectively) and anxiety symptoms as measured by the BAI ( $d = 0.67$  and  $d = 0.41$  respectively); no significant differences were noted between the two treatment groups on overall quality of life ( $d = -0.62$  and  $d = -0.60$  respectively; Craigie & Nathan, 2009). Another study found no differences in outcome measures of depressive symptoms at end-of-treatment or at follow-up between individuals receiving individual vs. group CBT. While participants tended to prefer individual CBT at the start of treatment, no differences were observed in overall satisfaction at the end of treatment or in overall attrition between the individual and group CBT conditions (Brown et al., 2011). Additionally, group CBT may be more cost-effective for treating depressive disorders (Brown et al., 2011; Tucker & Oei, 2007) and in treating children, but it appears to be less cost-effective than individual therapy for alcohol/substance dependence, anxiety disorders, and social phobias (Tucker & Oei, 2007).

### **Cognitive Behavioral Therapy (CBT) for Caregiver Burden**

There is a significant amount of literature that supports the use of CBT for the treatment of caregiver burden among primary caregivers of persons with dementia diagnoses, with moderate-to-large effect sizes from meta-analytic research (Beck et al., 2011; Kwon et al., 2015; Pinquart & Sörensen, 2006). Not only have individual studies found CBT to be beneficial and efficacious at reducing overall levels of caregiver burden (Ali & Bokharey, 2015; Davis et al., 2012; Dissanayaka et al., 2017; Kwok et al., 2014), but caregivers have also reported significant reduction in prevalence and severity of BPSDs and BPSD-related distress and increased self-efficacy in controlling upsetting thoughts and reactions towards the care-recipient (Kwok et al., 2014).

With regards to caregiver burden, both individual and group-based CBT appear to be effective – individual psychotherapy tends to be more individualized and is able to be tailored to the patient’s individual needs. As a result, while they are both effective, individual CBT tends to produce larger observable treatment-related effects (Pinquart & Sörensen, 2006). However, as previously discussed, group therapy is advantageous over individual psychotherapy in that it fosters and promotes social support among like-minded peers (Yalom & Leszcz, 2005) who, in this particular case, have experienced similar life circumstances and life-stressors (e.g., becoming primary caregivers of persons with dementia). This is important to note, because according to Mallinckrodt (1989), “...for members of theme groups who have experienced the same life stresses, mutually exchanged support may be more effective than the same type of support provided by persons outside the group who have not experienced the stressor” (p. 171). Taking into consideration that social support is a strong moderating factor in therapeutic interventions (Beckner et al., 2010; Röhrle & Strouse, 2008; Steketee, 1993; Thrasher et al., 2010), and that social support is typically one of the many important factors in therapeutic experiences per the patients’ reports (Yalom & Leszcz, 2005), group-based CBT becomes a likely candidate for providing an efficacious treatment method for the reduction of caregiver burden.

While results by Kwok and colleagues (2014) provide strong theoretical support for online CBT in the reduction of caregiver distress ( $d = 0.66$ ), no studies appear to have been conducted to date examining the efficacy of online-administered group CBT for the treatment/reduction of caregiver burden among primary family caregivers of persons with dementia.

## **Empirically Informed Conceptualization of Caregiver Burden: Information-Processing Theory and Social Learning Theory**

Caregiver burden is a complex and multidimensional experience, arising from multiple potential sources. From one perspective, the notion of role captivity discussed previously causes a caregiver to essentially forfeit a large part of their identity to the absorption of the caregiver role, leading to feelings of being trapped and helplessness in a constantly stressful situation and environment (Aneshensel et al., 1993). Caregiving demands often exceed one's innate coping resources. As burden persists, it becomes a significant source of stress and strain in its own right, leading to further feelings of helplessness and hopelessness within the caregiver (Tremont et al., 2008). In addition, being a caregiver to someone with dementia may lead to the development of anticipatory grief – as someone witnesses a loved one undergo significant cognitive and physical decline and become increasingly dependent on others, one may begin to anticipate the grief of losing his/her care-recipient to the disease progression. This is further complicated by the subjective feeling of “losing” the care-recipient due to cognitive decline, personality changes, and memory loss due to dementia. As a result, this anticipatory grief further complicates the experience of stress, strain, and burden, and it further depletes presently available coping resources making individuals more susceptible to intense experiences of caregiver burden and potential psychopathology (Holley & Mast, 2009).

It was hypothesized in this study that important potential maintenance cycles exist within the experience of caregiver burden. However, it is important to also recognize how caregiver burden develops and leads to these complicating experiences. Using a combination of information-processing theory and social learning theory, the theoretical foundations of CBT (Beck, 1991; Beck, 2011; Cully & Teten, 2008), this study sought to provide an empirically

informed theoretical conceptualization of caregiver burden which was used to guide therapeutic treatment planning.

As previously discussed, information-processing theory posits that the mind receives input via the senses, processes that input based on prior schemas (i.e., core beliefs), and informs cognitive and behavioral output/responses (Axelrod, 1973). When a person becomes a caregiver for a loved one with dementia, their relationship with and prior knowledge of that person often influence how they are to respond to the increased demands of the care-recipient. As a result, denial of specific dementia-related demands may surface, leading to automatic thoughts of “he/she can still perform this task,” “he/she does not really need my help with this,” or “things will get better” (Alzheimer’s association, 2019; Tang et al., 2013); thoughts which are based on prior experiences (i.e., an experientially-informed schema) of the care-recipient’s abilities before the onset of dementia. Emotions evoked from these types of thoughts likely include frustration and anger. When left unchecked, these emotions can develop into helplessness and loss-of-self, as the experiences of increased care-recipient dependence and increased demands on the caregiver continue to conflict with internalized schemas of the care-recipient’s prior abilities while, at the same time, further depleting the caregiver’s resiliency and ability to cope (Gaugler et al., 2007).

With depleted resources for coping, caregivers may begin to experience further feelings of helplessness and hopelessness. At this point, their identity as a caregiver begins to clash with their personal sense of identity and self. To cope with this, caregivers alter their identity and identify themselves primarily by their roles as caregivers. However, this identity is not at peace with their prior sense of self, nor is it typically in-line with their relational identity with their care-recipient (e.g., child-to-parent, spouse-to-spouse, sibling-to-sibling, etc.). With caregiving

experiences continually conflicting with internalized schemas and sense(s) of identity, further distress and feelings of burden are experienced as a result of continued faulty situational appraisals (Savundranayagam & Montgomery, 2010).

Within social learning theory, maladaptive behavioral patterns are inadvertently reinforced when they are congruent with core beliefs and schemas (Cully & Tetten, 2008). In the case of caregiver burden, caregivers are attempting to fully integrate their identities as caregivers. In doing so, they create a new internalized schema to make sense of their primary role as caregiver. Behaviorally, they fully engage with their role as caregiver, devoting all of their time and energy to performing caregiver-related tasks. While this may lead to potential maladaptive behaviors such as social withdrawal, lack of caring for oneself, and behavioral disengagement, all of which lead to further experiences of strain and burden, these behaviors are ultimately (and maladaptively) reinforced by the caregiver's internalized schema and identity as a caregiver (Savundranayagam & Montgomery, 2010).

At this point, role captivity begins to develop. As caregivers deplete their resources for coping with strain and for coping with identity discrepancies, they become captive by their role as caregiver (Aneshensel et al., 1993). Caregivers cease to engage in self-care and pleasant activities while ceasing to allow others to provide assistance or respite – as doing so would be incongruent with their internalized identity as a caregiver (Aneshensel et al., 1993). Caregiving demands and strains now exceed any coping resources the caregiver may be able to employ (Tremont et al., 2008), and anticipatory grief for both the future death of their care-recipient and the resulting dissolution of their caregiver identity further complicate the experiences of caregiver burden (Holley & Mast, 2009), thus leading to the development of depressive and anxious symptoms alongside experiences of caregiver burden (Cooper et al., 2008).



## Statement of Purpose & Study Aims

The purpose and primary aim of this study was to examine the preliminary feasibility of an online, group-based, multi-component, integrative CBT manualized treatment protocol for the reduction of caregiver burden among primary caregivers of persons with dementia diagnoses. In examining the differences between a pilot versus a feasibility study, Arain and colleagues (2010) suggest that the definitions of these two terms often become confused or conflated, suggesting that a major problem in the scientific community is the lack of clear distinction between the two terms. Based on their narrative review of the literature, Arain and colleagues (2010) proposed that “feasibility studies” are characterized by increased flexibility in the study protocol, with the primary goal of the study being to determine if future efficacy pilots and RCTs may be conducted; there may or may not be a control condition. Pilot studies, on the other hand, should be designed after a specific program/protocol is determined to be feasible either through a separate feasibility study or through empirically informed program protocols that already ensure feasibility of the program/protocol administration.

Other researchers also further this discussion on feasibility versus pilot/pilot-RCT style studies. While exact consensus regarding these definitions has yet to be determined in the current body of literature (Freeland, 2016), the general understanding is that feasibility studies should answer the question, “Can this [intervention/design] work?” (Bowen et al., 2009; Freeland, 2016; Orsmond & Cohn, 2015; Tickle-Degnen, 2013). In operationalizing the assessment of the question “Can this work?” Bowen and colleagues (2009) suggest that feasibility studies should focus on the following characteristics of an intervention: acceptability (participant satisfaction), demand (there is a stated or empirical need for the intervention), ability for the intervention/design to be implemented as planned (this can also be measured by study- or

treatment-specific characteristics), practicality (whether an intervention protocol or research design can work with available resources of participants; may be measured by participant retention), and ability for the protocol to be integrated with existing infrastructure. Additionally, phase two (or follow-up) feasibility studies may build upon these aspects as well as further characteristics: adaptation (further testing after incorporating necessary changes in various design areas as needed after initial testing) and expansion (examining whether the intervention/protocol can expand into further studies; may be expounded upon in phase two feasibility studies alongside adaptation). For the sake of this study, analysis of adaptation and expansion were not included, as they are typically reserved for phase two feasibility studies.

Additionally, feasibility studies often operate from a perspective of limited efficacy. While many authors suggest that feasibility studies can (and often do) include objective symptom-based outcome measures across treatment/intervention time (Bowen et al., 2009; Freeland, 2016; Orsmond & Cohn, 2015; Tickle-Degnen, 2013), these objective symptom-based measures are rarely the central focus of feasibility study results. Instead, the results of feasibility studies should focus on suggesting further changes (as needed) for further empirical testing of the protocol to ensure optimal feasibility in future pilot/pilot-RCT tests of efficacy (Bowen et al., 2009). The reason for this is that feasibility studies are not expected to have large sample sizes to justify powerful null hypothesis testing or generalizability of results to target populations (Tickle-Degnen, 2013). The purpose of feasibility studies is to assess whether an intervention protocol or research design can work in larger scale studies and are usually conducted when there is little to no empirical evidence on that particular intervention or design protocol. As a result, effect sizes in the literature often do not exist for feasibility studies to include accurate power analyses or projections (Freeland, 2016), as was the case with this study.

Because so little research presently exists for the feasibility of theoretically informed, online, synchronous group therapies for caregiver burden, this study could not be framed as a pilot test, RCT, or other test of treatment efficacy, and therefore must have focused on the preliminary feasibility of the protocol administration and design. The specific aims and hypotheses for this study were created in accordance with this classification.

### ***Hypotheses***

The primary research question of interest in this study was as follows: could the manualized group treatment protocol be implemented in a manner that is feasible for implementation in future pilot/RCT studies? To answer this question, specific aspects of feasibility were identified: feasibility of the recruitment plan (i.e., study/design implementation), ability for the manualized treatment protocol to produce a therapeutic group climate (as operationalized by perceived social support, positive therapeutic alliance, group cohesion, and group engagement; i.e., protocol implementation), participant retention (i.e., study practicality), participant satisfaction (i.e., study acceptability), and perceived burdensomeness (i.e., study integration).

The first hypothesis was that the recruitment plan, as outlined below, would yield the target number of participants ( $N=15$ ) within a 12-month period (see section *Recruitment of participants* for more information).

The second hypothesis was that the online CBT group therapy would be able to produce a positive therapeutic climate, as assessed by increased levels of perceived social support, perceived group cohesion, the development of a positive therapeutic alliance, and positive attitudes and engagement towards the group among group members from pre-test to post-test.

The third hypothesis was that this study would maintain adequate participant retention. Retention was operationalized as participants completing the entire course of treatment (i.e., eight weeks) without dropping out or otherwise self-discontinuing. Participants who started this study but were withdrawn by the research administrator (due to risk/safety issues or change in eligibility status) would not have been included in this analysis, but instead would have been reported separately. Across multiple meta-analyses of group therapy for varying psychological presenting concerns, attrition (drop-out) rates appear to range from 15-28% on average, with some variability for presenting concerns (e.g., group therapy for personality disorders tends to see higher attrition rates than anxiety-focused groups; Dixon & Linardon, 2019; Hans & Hiller, 2013a; Hans & Hiller, 2013b; Imel et al., 2013; Ong et al., 2018). Therefore, the target retention rate for this study was set for at least 80% (i.e., no more than 20% participant attrition).

The fourth hypothesis was that the online CBT group therapy would produce positive levels of satisfaction towards the therapy among group members, as assessed at post-treatment.

The fifth hypothesis was that the utilized intervention protocol would not create significant levels of perceived burdensomeness among participants. In this case, burdensomeness was operationally defined as a level of effort and energy expenditure as a result of participation that in turn increases participants' levels of reported stress (Lingler et al., 2014).

Lastly, a secondary research question of this study was as follows: could this treatment protocol reduce overall levels of caregiver burden, anxious symptoms, depressive symptoms, and role captivity among participants? While not a primary focus of this feasibility study, specific outcome measures were also assessed at multiple time points across treatment (measures of caregiver burden, depressive symptoms, anxious symptoms, and role captivity). Even with the understanding that feasibility studies typically operate from a stance of low statistical power and

limited efficacy (Bowen et al., 2009; Freeland, 2016; Orsmond & Cohn, 2015; Tickle-Degnen, 2013), it was still important to include and observe any potential changes in symptom-based measures. As a result, an exploratory sixth hypothesis was that the treatment protocol would reduce levels of caregiver burden, depressive symptoms, anxious symptoms, and role captivity across treatment.

This study ultimately sought to add to the current body of empirical knowledge by exploring a new, cost-effective, online, multi-component, theoretically informed, and integrative treatment modality for a significant public health issue. To date, few if any studies have examined a theoretically informed, synchronous, online, group-based therapeutic modality for the specific reduction of caregiver burden among primary family caregivers of persons with dementia. This study sought to fill this gap in the empirical body of knowledge while also establishing preliminary feasibility for a new, potentially efficacious method of treatment for an in-need population.

## **CHAPTER II**

### **METHOD**

#### **Sample**

Participants for this study were sampled from the following sites: Neuropsychological Services of Tidewater (Virginia Beach, VA), Sentara Neuropsychological Services (Norfolk, Virginia Beach, and Hampton, VA locations), and Bon Secours Neurology (Norfolk, VA). Individuals who identified as primary family caregivers of persons with dementia were the target population for this proposed study.

Because so little research existed at the time of this study on theoretically informed online group therapies for the reduction of caregiver burden among primary family caregivers of persons with dementia, an accurate power analysis could not be conducted, as there were no equitable effect sizes from which to estimate projected or target power for this study. This was also consistent with the literature on feasibility study designs given the stance of limited efficacy described previously (Freeland, 2016). This study attempted to recruit a minimum of 15 participants in accordance with recommendations for feasibility studies set forth by Eaton and colleagues (2018), who suggest “a sample of 12-16 participants...can provide preliminary insight into the feasibility and acceptability of a novel [treatment] arm before initiating a larger study” (p. 4).

#### **Institutional Review**

This study was submitted to and approved by the institutional review board (IRB) of Eastern Virginia Medical School (EVMS). Proof of IRB approval was provided to each of the five recruitment sites, all of whom deemed this documentation sufficient without need for further approval from separate IRBs or review committees.

## Procedures

### *Treatment Condition: CBT Group Treatment*

The online manualized group-based CBT treatment protocol within this study was designed to be a multi-component, integrative treatment approach. It included core tenants of CBT, such as identifying, challenging, and restructuring negative automatic thoughts, but it also included additional intervention techniques such as education on caregiver burden and caregiver-related stress, relaxation strategies and mindfulness as coping strategies, behavioral activation, supportive interventions, and process-oriented interventions. By providing a multi-component, group-based intervention, this manualized treatment approach was designed to provide optimal care (Acton & Kang, 2001) in a cost-efficient manner (Brown et al., 2011; Tucker & Oei, 2007). The CBT treatment was provided across eight weekly sessions, each lasting 60 minutes in duration, for a total of eight hours of direct intervention. Throughout all sessions, open discussion and group support was encouraged by the group facilitator to foster a supportive and interactive group environment (Beckner et al., 2010; Röhrle & Strouse, 2008; Steketee, 1993; Thrasher et al., 2010). In congruence with the empirical conceptualization of caregiver burden outlined previously, the CBT group treatment was designed to incorporate techniques and strategies to increase distress tolerance and increase sense of agency/independence for the purpose of reducing perceived sense of role captivity, thus reducing overall levels of caregiver burden. Treatment sessions were delivered via Bluejeans online meeting platform. Specific information about each individual session – as well as how each session-based intervention addressed caregiver burden in accordance with the aforementioned empirical conceptualization – follows:

**CBT Session One.** Session one consisted of a group introduction, orientation to the group therapy, rules/norms of the group sessions, and education on caregiver stress. According to the Alzheimer's Association (2019), there are 10 primary symptoms of caregiver stress for caregivers of persons with dementia: (1) denial about the care-recipient's diagnosis; (2) anger, either towards the care-recipient or towards others; (3) social withdrawal; (4) anxiety about the future and about providing adequate care; (5) depression or feelings of hopelessness; (6) fatigue or physical exhaustion; (7) sleep disturbances; (8) irritability, which may lead to outbursts towards the care-recipient or others; (9) difficulty concentrating; and (10) physical health problems. The primary purpose of this session was to provide education about caregiver stress to bring attention to specific symptoms that group participants may have (a) experienced in the past or (b) were currently experiencing at the time of treatment in order to build insight into individuals' experiences of caregiver burden and distress. Therapeutic research has shown that insight into a problem can be a beneficial process into creating necessary changes – a trend which has remained consistent over the past several decades (Høglend & Hagtvet, 2019; Friedlander, & Kaplan, 1956; Reid & Finesinger, 2006). Different types of insight foster different therapeutic significance. In this case, the goal of the education of caregiver stress was to provide insight into signs to foster significance. According to Reid and Finesinger (2006), signs are recognizable experiences that signify and function as evidence for a greater significance. In this case, the signs of caregiver distress (Alzheimer's Association, 2019) represent signs that group members were likely to be experiencing. By fostering insight into these signs, group members could begin to recognize the significance of these stress-related symptoms (i.e., the signs), thus promoting a desire for movement towards change (Reid & Finesinger, 2006). Group participants were then encouraged to track their experiences of caregiver distress throughout the



course of CBT treatment to promote the continued development of insight into these signs. For full details on session one, see Appendix J.

**CBT Session Two.** Session two of the manualized CBT intervention was centered around the topic of relaxation strategies. The session began with education on relaxation strategies, education on how relaxation is beneficial for reducing overall levels of stress (Beck, 2011), and provided in-group examples of three common relaxation strategies within the therapeutic literature (deep breathing, progressive muscle relaxation, and guided imagery; Graffam & Johnson, 1987; Watson et al., 1998). Relaxation strategies have been implemented into interventions for caregiver burden and have produced positive effects at reducing levels of stress and strain (Bourgeois et al., 2002; Coon & Evans, 2009; Davis et al., 2004). Relaxation training is also included in many CBT manualized treatments for managing stress or strain, as relaxation helps to alleviate stress/strain by actively promoting the release of physical tension, enervating the parasympathetic nervous system, and decreasing physiological arousal, thus reducing stress in-the-moment and over time (Murphy et al., n.d.). Within the context of caregiver burden and caregiver-related stressors, relaxation strategies would allow caregivers to begin lowering their levels of physical stress/strain/tension which likely contributed to their overall levels of caregiver burden. Some relaxation strategies, such as deep breathing, could also be utilized in-the-moment when caregivers were faced with a particularly distressing experience outside of sessions, thus increasing overall levels of distress-tolerance and distress coping (Kraemer et al., 2016). For full details on session two, see Appendix K.

**CBT Session Three.** Session three of the manualized CBT intervention was focused on mindfulness. Mindfulness as an intervention traces its roots to Eastern contemplation. It is defined as being intentional with where one's attention is directed, having one's mind in the

present moment (rather than in the past/future), and redirecting attention in a non-judgmental manner (Shapiro et al., 2006). This definition encompasses what are known as the three axioms of mindfulness: attention, intention, and attitude (Shapiro et al., 2006). As a therapeutic intervention, mindfulness serves to promote a nonjudgmental frame of mind towards one's surroundings, thoughts, and emotions, while enhancing focus on the present moment, allowing one to "disidentify from the contents of consciousness (i.e., one's thoughts) and view his or her moment-by-moment experience with greater clarity and objectivity" (Shapiro et al., 2006, p. 377). When this mental perspective shift occurs, participants often find that their overall levels of stress, strain, worry, and anxiety decrease because they become more attuned with the present moment, while thoughts about the past/future become less controlling (Shapiro et al., 2006). While mindfulness alone has not produced significant decreases in caregiver burden, as it is a single-component intervention on its own, studies have suggested that integrating mindfulness with additional interventions and strategies may produce more significant effects (Liu et al., 2017; Mamani et al., 2018). Mindfulness may be effective for reducing caregiver burden within the context of a multi-component intervention because it can help increase distress tolerance, increase coping abilities, and decrease overall levels of enthrallment with caregiving-related stressors. By detaching caregivers from future-oriented and caregiving-related stressors, mindfulness has been shown to produce significant reductions in perceived levels of role captivity as well (Hagemann et al., 2019). For full details on session three, see Appendix L.

**CBT Session Four.** Session four focused on behavioral activation via pleasant activities. Much like the sessions before this, this was a skills-based, psychoeducational session, integrating education and support with the behavioral skills focus of behavioral activation. The session began with a discussion and education about pleasant activities and their role in stress reduction.

Participants were encouraged to discuss and schedule at least two pleasant activities for the following week, one for themselves and one with their care-recipient (safety was also discussed and encouraged during this process). In addition, participants were encouraged to discuss barriers to engaging in pleasant activities and plans to circumnavigate such barriers. Behavioral theories state that people experience depressed mood due to a disruption in normal behavioral patterns, resulting in lower positive reinforcement and decreased sense of mastery and enjoyment, heightened sense of critical self-awareness, and behavioral withdrawal (Lewinsohn et al., 1985). People with high levels of caregiver burden are highly prone to experiencing this same disruption in typical behavioral patterns, thus likely leading to the high rate of depressive symptoms among this population. As a result, interventions utilizing behavioral activation via pleasant activities have produced reductions in caregiver burden, as these interventions attempt to reinstate a sense of normal/adaptive behavioral patterns, thus instilling a sense of mastery and life satisfaction (Au et al., 2015) and reducing perceived levels of role captivity. In addition, incorporating behavioral activation and pleasant activities immediately before the exploration of automatic thoughts and thinking patterns (see sessions five and six) allowed for a more targeted exploration of negative/maladaptive thoughts in the context of targeted behaviors which may have contributed to experiences of caregiver burden (Dimidjian et al., 2011). For full details on session four, see Appendix M.

**CBT Session Five and Six.** Both sessions five and six were focused on identifying, challenging, and reframing negative automatic thoughts. Negative automatic thoughts represent the uppermost layer of the cognitive behavioral framework, as discussed previously (Beck, 2011). According to Beck's framework, negative emotionality is ultimately the result of negative automatic thoughts in response to a faulty appraisal of a given situation (Beck, 2011). By

challenging and reframing these negative automatic thoughts, one can begin to think more positively and realistically, rather than being caught in a torrent of negative thoughts, thus improving one's emotional well-being and behavioral functionality (Beck, 2011; Beck Institute, n.d.). Session five focused predominantly on identifying negative thoughts, while session six focused predominantly on challenging and reframing these thoughts. Even though these sessions can be distinct in their discussions, identification and challenging/reframing of negative automatic thoughts may not always be a linear process in group therapies, with discussions often circling back from challenging/reframing to identification (Murphy et al., n.d.). Therefore, these two sessions were grouped together in this manualized protocol to facilitate this nonlinearity. Interventions for caregiver burden that incorporate CBT-based thought identification and reframing/challenging have been found to produce significant reductions in caregiver burden (Beck et al., 2011; Kwon et al., 2015; Pinquart & Sörensen, 2006). Within the cognitive behavioral framework, identifying and modifying negative automatic thoughts and cognitive distortions are principal mechanisms of action to reducing levels of distress and maladaptive thinking patterns which may be fueling psychopathology (Beck, 2011) – in this case, caregiver burden. The modification of maladaptive thinking patterns into more realistic, adaptive patterns of thinking allows individuals to approach potentially stress-inducing situations with more accurate appraisals, thus decreasing levels of distress (Beck, 2011). When coupled with interventions from previous sessions that increase distress tolerance and personal sense of agency, caregivers would have been more likely to re-establish a sense of self-identity and personal sense of mastery (Beck, 2011; Dimidjian et al., 2011) within the caregiving context, thus reducing levels of role captivity and caregiver burden. For full details on sessions five and six, see Appendix N.

**CBT Session Seven.** Session seven was entitled “problem solving with problem behaviors;” however, this session was not an educational session surrounding how to cope with BPSDs. Instead, this session was designed to be open-ended for all group members to discuss BPSDs that they may have experienced with their care-recipient, receive emotional and social support from the group facilitator(s) and other group members, and discuss amongst themselves in a supportive environment how these BPSDs might be managed or approached. Whereas previous sessions have been predominantly skills-based, the focus of session seven was on further fostering and utilizing group social support in-the-moment from a more interpersonal process perspective. While this session could have been placed earlier in the treatment protocol, it was important to have this process- and support-heavy session towards the end of the intervention schedule. The previous sessions served to build and enforce group dynamics, social support, and group cohesiveness (Yalom & Leszcz, 2005) in a way that this session could capitalize on these aspects in an optimal manner. Given the moderative quality of social support on the effectiveness of group-based interventions (Dadds & McHugh, 1992; Mallinckrodt, 1989; Steketee, 1993; Thrasher et al., 2010; Yalom & Leszcz, 2005), this session served to increase the impact of previous sessions and provided an environment in which like-minded peers could come together in support of one another. When taken into context of previous sessions designed to increase distress tolerance, coping repertoire, mastery, and agency and decrease role captivity and caregiver burden, this session was believed to increase these effects and the overall impact of the treatment protocol itself (Mallinckrodt, 1989; Yalom & Leszcz, 2005). For full details on session seven, see Appendix O.

**CBT Session Eight.** Session eight of the CBT treatment protocol was the concluding session. The central focus during session eight was to review the treatment thus far, discuss what

group members found most helpful, and allow group members to process, reflect upon, and discuss any treatment gains they may have noticed thus far in an open and supportive group environment. According to Yalom and Leszcz (2005), the final session of group therapy is incredibly important. Throughout the therapeutic process, group members form connections and relationships with one another; the termination of these relationships, which often naturally occurs with the termination of therapy, can be a painful process for some participants – especially when those relationships serve as their primary source of social support in trying times. As a result, it is important for the final session of any group therapy treatment to focus on this and allow for group discussion of emotions surrounding the termination of treatment (Yalom & Leszcz, 2005). While this final session discussed the treatment thus far and how the caregivers planned to utilize the information gained in their future lives, it was equally important to discuss the in-the-moment emotions and thoughts surrounding treatment (and relationship) termination (Yalom & Leszcz, 2005). In addition, this session served purposes of termination planning and relapse prevention by dedicating time for targeted group discussion on specific strategies learned in previous sessions to continue implementing after treatment cessation – an important aspect of maintaining treatment gains post-treatment (Beck, 2011). For full details on session eight, see Appendix P.

### ***Recruitment of Participants***

Participants were recruited using flyers posted at each of the recruitment sites. Flyers were included in patient waiting areas, patient examination and testing rooms, as well as included with any reports provided during feedback sessions. Clinicians at each recruitment site were also encouraged to include electronic versions of the recruitment flyer in e-communications with clients they saw via telehealth modalities. In addition, clinicians employed through the

recruitment sites were informed of the study and provided with a list of the study's "frequently asked questions (FAQs)" to give providers information about the study should prospective participants ask any questions. The providers at each recruitment site informed family caregivers of persons with established dementia diagnoses of this study. Interested individuals were then given the contact information of the research administrator to undergo a phone screening. Prospective participants were deemed eligible if they met the following inclusion criteria for this study: (1) the caregiver was an adult between the ages of 18-85; (2) the caregiver identified as the primary caregiver of a person with dementia; (3) the identified care-recipient was not currently enrolled in a long-term care facility or receiving other institutional-based care; (4) if the caregiver utilized the services of respite care on a regular basis, it could not exceed more than 10 hours per week; (5) the caregiver was a direct family member of the care-recipient (e.g., parent, child, spouse/partner, sibling, aunt/uncle, niece/nephew, family member by-law, etc.); (6) the caregiver must have been available during the group treatment scheduled time(s); (7) the caregiver scored 36 or above on the Caregiver Burden Inventory (CBI; see below); (8) the caregiver had regular and reliable access to internet connection with a web-cam, either via desktop computer, laptop computer, smartphone, tablet, or other electronic device to facilitate full engagement into the online group therapy format; and (9) the caregiver was able to set aside one hour/week during the designated treatment time in a private space with little-to-no distractions to facilitate full engagement in the group treatment.

During the phone screening, all participants were screened for eligibility based on the above inclusion criteria, and they were then administered the Caregiver Burden Inventory (CBI; see section entitled, *Instruments*). Prospective participants must have scored at least 36 or above on the CBI to participate in this study; this CBI cut-off score was based on prior research which

established that individuals who score near or above 36 on the CBI are in need of respite or other interventions to reduce global levels of caregiver burden (Novak & Guest, 1989). If deemed eligible, all participants were then provided with further information over the phone about the research study. The research administrator informed them of the study details, discussed informed consent, and allowed the prospective participant to ask any questions they may have had. The prospective participants then received a link to a RedCap survey which contained the informed consent form for them to read through carefully and electronically sign. Following this, they completed additional baseline questionnaire assessments via Qualtrics.

During the screening appointment, all prospective participants were informed of the importance of being able to set aside the treatment time and have a room/area in their home or other private location with little-to-no distractions. Participants were also encouraged to make separate arrangements during the treatment time for their care-recipients to be supervised if needed. This was to allow for the greatest capacity for engaging with the group treatment. Participants who were not able to confidently engage in the group in such a manner were deemed ineligible to participate. Any individual who was deemed ineligible to participate in this study for any reason outlined in the above inclusion criteria was provided with external referral sources should they wish to receive treatment/intervention for caregiver related stress elsewhere. These external sources included sources for educational information (e.g., Alzheimer's Association website [alz.org](http://alz.org)), locations near them from which they could receive psychotherapeutic treatment, and instructions on contacting their referring provider for information on additional services if needed. The research administrator provided this information over the phone at the conclusion of the screening session and via email if the individuals provided verbal consent to be contacted via email.



Once screened in, participants were assigned to a therapy group. Therapy groups were set to contain 4-8 participants each. Data among the literature is ultimately mixed on what constitutes an “ideal” group size. Yalom and Leszcz (2005) suggest that group size can vary greatly depending on the purpose of the group and length of the group. They suggest that groups meeting for longer duration may have larger group sizes, and groups with longer meetings may also benefit from larger group sizes. However, shorter duration groups may benefit from smaller group sizes. They also suggest that while psychoeducational groups may include larger group sizes, as group interaction may not always be a key component in purely psychoeducational groups (Yalom & Leszcz, 2005), the integrative and multi-component treatment protocol employed in this study sought to incorporate group engagement and discussion, therefore lending for smaller group sizes (Yalom & Leszcz, 2005). There currently are no empirically informed recommendations on “ideal” group size for telehealth-based group interventions.

### ***Participant Retention Plan***

It was important that participants who were eligible and enrolled in this study completed the intervention. The manualized CBT treatment protocol was designed so that each session built off the previous session, and the therapeutic effects built upon previous therapeutic effects. That being said, failure to attend sessions could have ultimately led to diminished therapeutic benefits for the participant(s). Consistent group member presence at the weekly sessions would also help to build a healthy group climate and group cohesion – an important mechanism of action for group therapies (Yalom & Leszcz, 2005). As a result, frequent absences of group members would have negatively impacted the ability for the group to form cohesive bonds with one another and thus therapeutic effects could have been diminished, making participant retention a high priority in this study.

Participants were informed during the screening session of the importance of attending all scheduled sessions, as this has been shown to improve overall group therapy attendance rates (Yalom & Leszcz, 2005). With this, they were asked if they could or could not set aside the one hour of treatment during the designated time every week. If the participant said they were unable to do so, then they were not deemed eligible to participate in this study (see section entitled Recruitment of Participants). All sessions were held on the same day/time every week, and a schedule was provided electronically detailing the dates and times of each weekly group therapy session. The group facilitator also called each participant the day before the scheduled group therapy session each week to remind them of the group therapy session's occurrence unless group members requested otherwise, and reminder emails with the Bluejeans session login information were sent out the morning of each session. If a participant was absent and did not provide the facilitator with a reason for the absence before the group session (either via email or phone call), the facilitator called the participant to discuss the absence and remind them of the next group session. If the participant did not answer the phone, a voicemail message was left, and an email was also sent to the participant requesting them to contact the facilitator as soon as possible.

The group facilitator kept track of how many sessions for which each participant was absent. Individuals who missed more than two group sessions would have been removed from this research study. As previously mentioned, missing therapy sessions diminishes the effects of the overall therapeutic intervention, and infrequent group participation reduces overall group cohesion and other important aspects of the group climate, thus having the potential to reduce therapeutic effects for other group members as well (Yalom & Leszcz, 2005). In the event an individual self-discontinued from this study, they would have been asked to complete the end-of-

treatment quality metrics, secondary outcome measures, and a measure of group satisfaction online via Qualtrics (see assessments below) to provide insight into potential reasons for self-discontinuation. Participants who were to be withdrawn from this study due to missing more than two sessions or who self-discontinue would also have been provided with three external referral sources (minimum) should they have wished to continue seeking treatment elsewhere. The group facilitator would have worked with them individually over the phone to provide additional sources of educational information (e.g., Alzheimer's Association website [alz.org](http://alz.org)) or locations near them from which they could receive additional psychotherapeutic treatment. This information would also have been sent via email after the phone call as well.

### ***Supervision Plan***

The primary group facilitator in this research study was an advanced doctoral student in a clinical psychology program who previously had experience facilitating both skills-based and process-oriented therapy groups. The facilitator was supervised by a licensed clinical psychologist at EVMS. The facilitator was in regular (i.e., at least weekly) contact with the designated supervisor regarding recruitment and intake of participants into the study during the recruitment phase(s). During the active treatment administration, the facilitator met in regular (i.e., at least weekly) supervision sessions for no less than 30 minutes in duration with the designated EVMS supervisor. While in-person supervision was preferred, due to the presence of the novel coronavirus disease 2019 (COVID-19) pandemic, considerations for safety of both the supervisor and supervisee permitted tele-based supervision via Bluejeans synchronous online meeting platform.

Additionally, the group facilitator wrote a summary of each group session in the form of a detailed group-session note which was provided to the supervisor no later than 24-hours after

the conclusion of that session. In the event of any risk-related evaluations, the facilitator would have been in contact with the designated supervisor immediately to discuss proceeding steps and a plan of action (see section below). All group session notes included aspects of the manualized intervention which were utilized and adhered to by the therapist to provide documentation of treatment fidelity. No group session notes included confidential or identifying information of research participants.

All participants were informed during the screening appointment that while the facilitator would make every possible effort to ensure confidentiality of the group sessions, information about individual sessions may be disclosed with the supervising licensed clinical psychologist due to the facilitator's student and trainee status. All participants verbalized understanding and agreed to this also as a part of providing informed consent to participate.

To ensure treatment fidelity, therapist adherence to the manualized treatment protocol was discussed in each supervision session. Treatment fidelity is often operationalized as having three separate components: therapist adherence, therapist competence, and treatment differentiation (Campbell et al., 2013; Schoenwald & Garland, 2013). Therapist adherence is defined as the therapist's ability to administer treatment in accordance with the prescribed protocol (in this case, in accordance with the manualized treatment procedures), while differentiation is one's ability to refrain from the use of proscribed behaviors/interventions that are not included within a standardized treatment procedure (Campbell et al., 2013). Therapist competence refers to the skill of the therapist in administering the prescribed treatment as well as their skill(s) in non-specific therapeutic interventions such as empathy, timing of interventions within the interventional processes, and facilitating/growing therapeutic alliance (Campbell et al., 2013). While most standardized measures of treatment fidelity require either live observation

or video observation from a non-biased rater (Schoenwald & Garland, 2013), these measures were not feasible to implement within the context of this study. Live observation was not recommended in order to preserve the true therapeutic climate, as the addition of observers within the group setting may have created tensions, apprehensions, or discomforts within the group (Yalom & Leszcz, 2005). Given that the group climate characteristics were a large component of this study, actions that could have artificially impeded the development of a fully-realized group climate could have artificially and adversely impacted these results. Video recording was also not feasible due to participant confidentiality.

As a result, formally assessing treatment fidelity posed a unique challenge within this study. To ensure treatment fidelity as much as possible, the aforementioned detailed group-therapy session notes included detailed information about the manualized intervention, adherence to the protocol, and the use of any proscribed intervention methodologies. These notes, along with other more specific details from each session, were discussed in supervision sessions to ensure treatment fidelity and adherence to the manualized treatment protocol throughout its implementation.

### ***Risk Assessment and Evaluation***

After participants reviewed informed consent, all participants were asked to provide a best contact phone number and the address at which they reside (and the address at which they planned to engage with the group therapy if it was different from their home address) in the event that emergency services needed to be called to their location for concerns surrounding impending suicidality, homicidality, or if Child/Adult Protective Services (CPS/APS) needed to be informed of suspected child abuse, elder abuse, or abuse of a disabled person. All participants were informed of this within the limits of therapeutic and research confidentiality as outlined by

the American Psychological Association (APA) ethics code and guidelines for clinical and research practices (APA, 2017).

In the event that the group facilitator suspected that any group member may have been experiencing suicidal/homicidal ideation, plan, or intent, the group facilitator would ask that group member to remain on the online Bluejeans group platform after the session concludes. Once the facilitator ensured that all other group members had left the session, the facilitator would have conducted a formal risk assessment. This risk assessment would have started with screening questions to assess broad levels of suicidal/homicidal ideation, plan, and intent. If any of these questions were answered in the affirmative, then the facilitator would have asked further questions to assess the nature of the ideation, intent, and plan, as well as means and access to various means for engaging in suicidal/homicidal behavior such as access to firearms, weapons, medications with overdose potential, or other lethal means. Other questions may have also been asked to evaluate history of suicidal/homicidal ideation or behaviors: past suicidal/homicidal ideation, past suicide attempts, previous hospitalizations due to suicidal ideation or attempts, frequency and intensity of ideation, etc.

If a participant was deemed to be of imminent risk for suicide, the facilitator would have immediately consulted with the designated licensed supervisor, after which they would have both discussed with the participant the need for hospitalization. If the participant declined to go to the hospital voluntarily, emergency services in their respective area would have been called, and emergency services would travel to the participant's location for an in-person evaluation and transfer to their local hospital. During this time, the participant would have been strongly encouraged to stay on the online group format with the facilitator to ensure safety.

If the participant was deemed of non-imminent risk for suicide, the facilitator would have still consulted with the designated supervisor to discuss plans moving forward. A safety plan could have been created collaboratively between the facilitator and the participant. Additionally, the participant could have been removed from this study and referred to more directed, in-person or individual therapy, as this group therapy may not have provided individuals with the treatment interventions needed to ameliorate suicide risk.

In the event abuse to a child, elderly, or disabled person was suspected, the facilitator would have again asked the participant to remain on the online Bluejeans session. After all other participants had left the session, the facilitator would have assessed further the suspected abuse. Once assessed, the facilitator would have consulted with the designated licensed supervisor to determine if a call to CPS/APS was warranted. The participant would have then been removed from this study and referred for more directed, individual therapy. All CPS/APS calls would have been made immediately after the assessment and supervisor consultation.

### ***Study Timeline***

In examining the literature for recruitment timelines within feasibility studies, there appears to be very little agreement on “best practices” for how long recruitment should remain open. Some studies suggest as little as six months, while others describe recruitment strategies that took place over multiple years (Lovato et al., 1997; UyBico et al., 2006). Additionally, one meta-analysis of recruitment strategies across multiple clinical research studies found that a very low percentage of clinical studies (14%) even reported the length or duration of their recruitment procedures (UyBico et al., 2006), leading to a general lack of information guiding future researchers in developing feasible and empirically informed recruitment schedules. Recruitment timelines are also noted to be significantly impacted by various outlying factors not necessarily

related the study procedures, such as researchers' time-constraints, institutional time-constraints, and time-constraints of funding and financial support (Lovato et al., 1997). As a result, it has been suggested in the literature that feasibility of recruitment should not always be determined by a timeframe, but rather a rate of recruitment within the time frame specified (e.g., monthly recruitment rate = number of participants recruited / number of months spent recruiting; Stewart et al., 2020).

Given this information, this study elected for a 12-month period of open and continuous recruitment, from October 2020 to October 2021. During this time, recruitment of participants was continuous and did not experience any breaks, pauses, or holds. At the start of recruitment in October 2020, only three of the five total sites were included in the data collection procedures (Neuropsychological Services of Tidewater in Virginia Beach, VA and Sentara Neurology Specialists locations in Norfolk, VA and Virginia Beach, VA). A fourth recruitment site (Sentara Neurology Specialists Hampton, VA location) was added in November 2020, and a fifth site (Bon Secours Neuroscience Center in Suffolk, VA) was added in January 2021. The additional two sites were added due to the unanticipated slow recruitment at that time and with the goal of expanding recruitment throughout the Hampton Roads region of Virginia in an attempt to meet the recruitment goal of this study ( $N=15$ ).

The first group therapy treatment arm began in early-March 2021 and continued through early-May 2021 (eight weeks, plus a one-week break between sessions four and five in observation of the Easter holiday in early April 2021). This group treatment took place at the same day/time each week and included four ( $n=4$ ) members. Additional group times were set aside for a second group treatment arm to be conducted; however, due to lack of recruitment (see



section Summary of Recruitment in Chapter III: Results), a second group treatment arm could not be initiated.

Recruitment remained open through October 2021 to allow for 12-months of continuous recruitment procedures. During this time, the research administrator maintained regular (i.e., at least monthly) contact with recruitment site liaisons to ensure the sites' ongoing participation and engagement with recruitment procedures. Upon the closure of recruitment procedures in October 2021, any participants who had provided consent to participate in this study but who were unable to initiate treatment due to lack of recruitment were contacted via phone and informed of the study's closure. Additional information regarding services for caregiver distress were provided, including educational information (e.g., Alzheimer's Association website [alz.org](http://alz.org)), locations near them from which they may receive psychotherapeutic treatment, and instructions on contacting their referring provider for information on additional services if needed.

### ***Instruments***

**Social Provisions Scale (SPS).** The SPS is a 24-item self-report inventory designed to assess various aspects of perceived social support. Participants responded to each item on a scale of one to four based on the extent to which they agreed with each statement (e.g., "There are people that I can depend on to help me if I really need it" could have been responded with *1 = Strongly disagree*, *2 = Disagree*, *3 = Agree*, or *4 = Strongly agree*; Cutrona & Russell, 1987; see Appendix E for full SPS). The SPS is designed to assess social support across six separate dimensions (not including total social support, which is calculated by the sum of all scale items): guidance (i.e., availability of confidants or authoritative others to provide advice), reassurance of worth (i.e., having skills and abilities acknowledged by others), social integration (i.e., there are others who share one's interests and concerns), attachment (i.e., feelings of safety and security in

close emotional bonds), nurturance (i.e., the sense of being needed in vital ways by other people), and reliable alliance (i.e., assurance that one can count on assistance being available if needed; each scale composed of four items; Cutrona & Russell, 1987; Mallinckrodt, 1989). According to the literature, internal consistency metrics for each of the subscales range from  $\alpha = 0.61$ - $0.76$ , with subscale test-retest reliability metrics ranging from  $r = 0.37$ - $0.66$ ; total test-retest reliability for the entire scale was measured at  $r = 0.59$  (Cutrona & Russell, 1987; Mallinckrodt, 1989). More recent studies have found internal consistency for the entire SPS to be stronger, with  $\alpha = 0.92$ , and adequate internal consistency within each subscale, with  $\alpha = 0.65$ - $0.76$  (Gottlieb & Bergen, 2010). Concurrent validity has been historically established, with correlations to similar scales ranging from  $r = 0.35$ - $0.45$ ; these correlations suggest that the SPS measures the constructs adequately while providing a novel perspective of social support which other measures may not provide (Cutrona & Russell, 1987; Gottlieb & Bergen, 2010).

For the purpose of this study, the SPS was used as a quality metric assessing the therapeutic intervention's ability to create a socially supportive group climate. Prior studies have shown that perceived social support is a significant and moderative factor within group therapy effectiveness (Beckner et al., 2010; Röhrle & Strouse, 2008; Steketee, 1993; Thrasher et al., 2010). Therefore, it was important to measure the extent to which this intervention instilled a sense of social support within the group climate and between participants to facilitate optimal outcomes (Yalom & Leszcz, 2005).

**Therapeutic Factors Inventory, Cohesion Scale (TFI-Coh).** The TFI is a large, 60-item self-report battery with 11 different subscales designed to assess various domains and factors of group psychotherapy (Lese & MacNair-Semands, 2000; Yalom & Leszcz, 2005). Participants responded to each item on a seven-point Likert scale based on the extent to which

they agreed with each statement (e.g., “We cooperated and worked together in group” could have been responded with *1 = not at all*, *2 = a little bit*, *3 = somewhat*, *4 = moderately*, *5 = quite a bit*, *6 = a great deal*, or *7 = extremely*; Lese & Macnair-Semands, 2000; See Appendix F for full TFI-Coh). While the full inventory assesses many different group psychotherapeutic factors, only the cohesion subscale (TFI-Coh) was utilized in this study.

The TFI-Coh contains nine items that directly assessed group member perceptions on the cohesiveness of the therapy group. Studies have supported its use in the literature and its agreement with the operational definition of group cohesion (Johnson et al., 2005; Yalom & Leszcz, 2005). Additionally, the cohesion subscale as a stand-alone measure has shown to demonstrate strong psychometric properties, with test-retest reliability of 0.93 and internal consistency  $\alpha = 0.90$  (Johnson et al., 2005). Given the historically established and strong psychometric properties and its use in the literature, the TFI-Coh was deemed an optimal measure of cohesion, and it was used in this study to assess a quality aspect of the online CBT group therapy and its ability to create a cohesive group climate through which the therapeutic intervention was implemented.

**Working Alliance Inventory, short form (WAI-SF).** The WAI-SF is a 12-item self-report assessment of the therapeutic alliance between a patient and the therapist. Participants respond to each item on a seven-point Likert scale based on the extent to which they agreed with each statement (e.g., “The therapist and I trusted one another” could have been responded with *1 = never*, *2 = rarely*, *3 = occasionally*, *4 = sometimes*, *5 = often*, *6 = very often*, or *7 = always*; Munder et al., 2010; see Appendix G for full WAI-SF). The WAI-SF has two separate versions – a client/patient-report and a therapist-report version – to assess perceptions of the working therapeutic alliance from both the client/patient’s and the therapist’s perspectives. For this study,

only the client/patient-report form was used. While the WAI-SF was originally developed for the individual therapeutic setting, it has seen empirical use in group therapy settings and maintained strong psychometric properties (Cook & Doyle, 2002; Crowe & Grenyer, 2008).

Factor analysis studies have shown that the WAI-SF contains three distinct factors/subscales: collaboration on task, agreement on goal, and affective bond. The scale as a whole has demonstrated positive convergent validity with other measures of working alliance (e.g., the Helping Alliance Questionnaire,  $r = 0.75$ ). The scale as a whole has demonstrated strong internal consistency ( $\alpha = 0.90$ ), as have each of the individual subscales ( $\alpha = 0.81$ - $0.85$ ; Munders et al., 2010). Given its strong psychometric properties and use in prior group therapy research studies, the WAI-SF represented an optimal scale to assess an important quality aspect of the CBT therapeutic intervention within this study – its ability to generate positive working alliance and therapeutic relationships between the therapist and the individual participants, thus allowing for greater impact of therapeutic results (Yalom & Leszcz, 2005).

**Group Attitude Scale (GAS).** The GAS is a 20-item self-report assessment of therapeutic attraction and engagement. Individuals responded to each item on a nine-point scale based on the extent to which they agreed/disagreed with each statement (e.g., “I did not feel a part of the group’s activities;”  $1 = agree$ ,  $9 = disagree$ ; Evans & Jarvis, 1986; see Appendix H for full GAS). The GAS has been shown to have strong psychometric properties, with internal consistency  $\alpha = 0.90$ - $0.97$ , and strong convergent validity with measures of group commitment (e.g., Group Environment Scale cohesion/commitment subscale,  $r = 0.69$ - $0.72$ ; Evans & Jarvis, 2012). Given the strong psychometric properties and its use in the literature (Marziali et al., 1997; Pisetsky et al., 2015; Taube-Schiff et al., 2007), the GAS was used in this study as a quality metric of the CBT group measuring participant engagement in the therapeutic process.

**Satisfaction with Therapy and Therapist Scale-Revised (STTS-R).** The STTS-R is a 13-item self-report assessment of overall patient satisfaction towards group therapy. Individuals responded to each item on a 5-point scale based on the extent to which they agreed with each statement (e.g., “I am satisfied with the quality of the therapy I received” could have been responded with *1 = strongly disagree, 2 = disagree, 3 = neutral, 4 = agree, or 5 = strongly agree*; Oei & Green, 2008). A factor analysis study revealed that 12 of the 13 total items load onto two distinct factors or subscales: one’s satisfaction with the therapy (ST) and one’s satisfaction with the therapist (SWT). Item 13 of the STTS-R acts as a stand-alone measure of overall perceived therapeutic outcomes (e.g., “How much did this treatment help with the specific problem that led you to therapy” could have been responded with *1 = made things a lot worse, 2 = made things somewhat worse, 3 = made no difference, 4 = made things somewhat better, or 5 = made things a lot better*; Oei & Green, 2008). Higher scores indicated greater levels of satisfaction. Internal consistency metrics from the literature demonstrate strong internal reliability for the measure as a whole ( $\alpha = 0.93$ ) and within both subscale factors, with ST  $\alpha = 0.90$  and SWT  $\alpha = 0.89$  (Oei & Green, 2008). Both satisfaction scales have also been shown to significantly correlate with changes in clinical outcome measures (e.g., Zung Self-Rating Depression Scale,  $r = 0.15-0.17, p < .05$ ; Beck Anxiety Inventory,  $r = 0.16-0.20, p < .01$ ; Oei & Green, 2008). The STTS-R appears to demonstrate strong psychometric properties and has been used within the group therapy literature (Curtin & Eacho, 2012), and thus was used as a quantitative measure of participant satisfaction towards the group therapy intervention in this study.

**Modified Perceived Research Burden Assessment (mPRBA).** The PRBA is a 17-item self-report questionnaire designed to assess perceived research burden among participants. It was

originally designed to be implemented at the start of a research study to assess projected perceived burdensomeness towards participating in a study; however, the measure can be modified and adapted into past tense (rather than future tense) to assess post-hoc perceived burdensomeness after participation in a study is complete (mPRBA; Lingler et al., 2014). All items were rated on a likert-type scale from one to five based on how much participants agreed with a given statement (*1 = strongly disagree, 5 = strongly agree*). The questionnaire includes two subscales assessing psychological burden (i.e., does the study create any additional stress/strain; “I felt that the researchers asked too many questions, or that the questionnaires were too much”) and logistical burden (i.e., study accessibility, cost-effectiveness, or time-involvement; “I felt that this study’s visits/sessions were too frequent”; Lingler et al., 2014), with a total burden scale being the sum of each subscale. The PRBA/mPRBA historically has been found to have strong discriminant validity with measures of perceived study satisfaction, with only modest correlations ( $r = -.29$ ) in research scenarios with low associated risk; the measure was also found to have good internal consistency within the literature, with average Cronbach’s  $\alpha = .87-.95$  (Lingler et al., 2014). While the measure has strong psychometric properties, it does not have standardized cut-off values for reported burden levels. However, the authors of the questionnaire insinuate that total burden scores under 30 represent low levels of perceived burdensomeness (Lingler et al., 2014). Therefore, this was used as the designated cut-off value for this study in determining low levels of perceived research burden (see appendix Y for full mPRBA measure).

**Caregiver Burden Inventory (CBI).** The CBI, which comprised one of the outcome measure in this study, is a 24-item self-report inventory designed to assess levels of caregiver burden, on which participants responded to each item on a scale of zero to four based on the

extent to which they agreed with each statement (e.g., “My care receiver is dependent on me” could have been responded with *0 = not at all*, *1 = very little*, *2 = moderately*, *3 = much*, or *4 = very much*; Novak & Guest, 1989; see Appendix B for full CBI). In its original validation study, factor analysis results revealed five distinct sub-factors, not including a total/global burden scale (i.e., sum of all scale items equating to overall levels of caregiver burden): time-dependent burden (i.e., burden related to the amount of time spent providing care), developmental burden (i.e., burden related to expectations surrounding one’s current place in life), physical burden (i.e., burden related to the physical strain of caregiving), social burden (i.e., burden related to aspects of one’s social life that may be suffering as a result of caregiving), and emotional burden (i.e., burden related to negative emotional experiences as a result of caregiving; Novak & Guest, 1989). While one study reported only four distinct factors, rather than five (Marvardi et al., 2005), a majority of the evidence surrounding the multidimensionality and validity of the CBI continue to support the five distinct factors above (Caserta et al., 1996; Greco et al., 2017; Novak & Guest, 1989). Studies support the internal consistency of the total scale and each subscale, with internal consistency values for each subscale factor as follows: time-dependent burden ( $\alpha = 0.85$ ), developmental burden ( $\alpha = 0.87$ ), physical burden ( $\alpha = 0.86$ ), social burden ( $\alpha = 0.69$ ), and emotional burden ( $\alpha = 0.81$ ; Caserta et al., 1996), and with the total burden scale having  $\alpha > 0.80$  (Marvardi et al., 2005).

While overall caregiver burden and the individual subscales demonstrate mild convergence with measures of depressive symptoms ( $r = 0.28-0.63$ ; Caserta et al., 1996), this is to be expected, as caregiver burden has been strongly associated with experiences of depressive symptoms within the literature (Acton & Kang, 2001; Gaugler et al., 2008; Pinquart & Sörensen, 2006). The level of convergence between the CBI and common measures of depressive

symptoms (e.g., CES-D), while low-to-moderate, are not so strong that the CBI ceases to measure a different construct (Caserta et al., 1996).

Unfortunately, the CBI does not have standardized cut-off scores or interpretive ranges as some symptomatic self-report measures do. Therefore, empirical guidelines for the use of the CBI were consulted for understanding normative severity. Novak & Guest (1989) suggest that individuals who score near or above 36 on the CBI total burden scale are at increased need for interventions to reduce overall levels of burden; as a result, this cut-off score was used as a minimum required score for eligibility in this study.

**Hospital Anxiety and Depression Scale (HADS).** The HADS is a 14-item self-report measure of both anxious and depressive symptoms, with seven items loading onto each of the two scales. Participants responded to each item on a scale of zero to three based on the extent to which they agreed with each statement within the past week (e.g., “I feel tense or ‘wound up’” could have been responded with *0 = Not at all*, *1 = From time to time / occasionally*, *2 = A lot of the time*, or *3 = Most of the time*; Zigmond & Snaith, 1983; see Appendix C for full HADS).

While the HADS was originally created and validated within an acute hospital setting (Zigmond & Snaith, 1983), many studies have since examined the validity and reliability of the HADS in community and outpatient treatment settings, finding that the psychometric properties continue to remain strong across these treatment settings (Bjelland et al., 2001).

Factor analysis studies continue to support the existence of two distinct factors, with seven items loading onto each, within the HADS: anxious symptoms and depressive symptoms (Bjelland et al., 2001; Zigmond & Snaith, 1983). While distinct, the two factors do demonstrate some convergence between them, with average correlations  $r = 0.56$  (Bjelland et al., 2001). However, this level of convergent correlation between the two subscales is to be expected, as



previous studies have found that anxiety and depression as constructs are typically correlated when measured together ( $r > 0.50$ ; Beck et al., 1988). While the two constructs are mildly correlated, the convergence between them is likely not enough to warrant consideration as non-distinct constructs (Bjelland et al., 2001).

Both subscales demonstrate strong internal consistency across the literature, with average Cronbach's  $\alpha$  values across studies as follows: depression subscale ( $\alpha = 0.83$ ) and anxiety subscale ( $\alpha = 0.82$ ; Bjelland et al., 2001). Additionally, both subscales demonstrate strong evidence for convergent validity with other measures of depressive and anxious symptoms respectively, with  $r = 0.49-0.83$  (Bjelland et al., 2001).

Given the strong evidence surrounding the validity and reliability of the HADS as a brief screening measure of both anxious and depressive symptoms, it was considered an optimal choice to include in this study. While the primary outcome measure in this study was caregiver burden (as assessed by the CBI), it was important to examine and assess potential comorbidities of caregiver burden, including anxious and depressive symptoms (Acton & Kang, 2001), as secondary outcomes. Additionally, because the HADS is brief and assesses both constructs with strong psychometric properties, its inclusion in this study served to reduce overall level of assessment burden on participants, rather than including two separate and potentially longer measures of anxious and depressive symptoms.

**Role Captivity Scale (RCS).** The RCS is a 3-item subscale within the Brief Measures of Secondary Role and Intrapsychic Strain Scale, developed by Pearlin and colleagues (1990). The entire measure consists of 94 Likert-scaled items and was created to assess for different areas of stress and strain related to caregiving in the context of Alzheimer's disease and other forms of dementias. The 94 items span various domains of stress and strain within the dementia

caregiving context, including care-recipient cognitive status, problematic behaviors, overload/burnout, relational deprivation, family conflict, job-caregiving conflict, economic strains, role captivity, loss of self, caregiving competence, personal gain, management of situation, management of meaning, management of distress, and expressive support (Pearlin et al., 1990). However, for the purpose of this study, only the three-item role captivity subscale (RCS) was used as to maintain relatively low assessment burden on the participants.

The RCS contains three individual Likert-scaled items which assess the caregiver's level of role captivity, or the extent to which the caregiver feels absorbed or trapped by their caregiving role. Participants ranked each item on a scale of one to four based on how often they experienced certain thoughts/feelings (e.g., "How much do you wish you were free to lead a life of your own" could have been responded with *1 = Not at all*, *2 = Just a little*, *3 = Somewhat*, or *4 = Very much*; see Appendix D for full RCS), with higher total scores representing higher levels of role captivity (Pearlin et al., 1990). Internal consistency metrics reported in the literature for the RCS suggest that it maintains strong internal consistency, with  $\alpha = 0.83-0.89$  (Lawrence et al., 1998; Noonan & Tennstedt, 1997; Pearlin et al., 1990). Additionally, the RCS has seen use in multiple studies as a stand-alone measure seeking to analyze the construct of role captivity within the context of caregiving for persons with dementia diagnoses (Aneshensel et al., 1993; Lawrence et al., 1998; Noonan & Tennstedt, 1997; Pearlin et al., 1990; Quinn et al., 2019; Zarit et al., 1998).

Because it is believed that role captivity is a crucial component in the experience of caregiver burden (see section, *Empirically Informed Conceptualization of Caregiver Burden: Information-Processing Theory and Social Learning Theory*), the RCS was incorporated into this study as a secondary outcome measure.

**Demographics Questionnaire.** This study included a demographics questionnaire, which each participant completed at the baseline assessment point. The demographics questions included were as follows: age (years), gender, race, marital status, occupational/employment status, education level, household income/SES, living with children under the age of 18, living with care-recipient (yes/no), relationship to care-recipient (e.g., spouse, child, parent, sibling, etc.), how long the participant has identified as a primary caregiver, an approximate number of hours per week spent providing care to the care-recipient, and if they were undergoing psychotherapy/counseling services or taking any prescribed medications for the management of stress, depression, or anxiety at the time of entering this study (see Appendix I for full Demographics Questionnaire).

### ***Assessment Schedule***

The above measures were administered at multiple time points throughout this study. The group climate measures (i.e., SPS, TFI-Coh, WAI-SF, and GAS) were administered after the first group session and again at the conclusion of the eight-week treatment intervention (i.e., post treatment) to assess changes in participant's perceptions of each group process (i.e., social support, group cohesion, therapeutic alliance, and engagement respectively) throughout the course of their group experience. These measures could not be administered before the start of the first group session, as each measure assesses specific processes that are only experienced within the context of the group therapy setting. These processes cannot exist before the start of treatment, and therefore can only be measured after the first treatment session at the earliest. This methodology has been supported within the literature (Carron & Brawley, 2000; Kacovski et al., 2013; May et al., 2008; Webber et al., 2008).



## CHAPTER III

### RESULTS

#### Summary of Recruitment

As discussed previously, this study recruited participants utilizing a direct referral process (Greenfield et al., 2014) from five community-based neurology and/or neuropsychology clinics located across four different cities within the Hampton Roads region of coastal Virginia: Norfolk (Sentara Neurology Specialists), Virginia Beach (Neuropsychological Services of Tidewater; Sentara Neurology Specialists), Hampton (Sentara Neurology Specialists), and Suffolk (Bon Secours Neuroscience Center). Staff members at each site were instructed to provide study-related information (advertisement flyer with a description of the study and contact information for the research administrator) to any primary family caregivers of persons with dementia who displayed or mentioned elevated levels of stress related to caregiving tasks. Recruitment of participants took place continuously for twelve months (October 2020 through October 2021) with a goal of reaching a target sample size of  $N = 15$ .

Over the course of the twelve-month recruitment process, a total of nine people contacted the research administrator to express interest, seven of whom met criteria for eligibility within this study and provided informed consent to participate. Of those, only four participated in this study (two could not participate due to failure to recruit enough participants for a second group; one provided informed consent but experienced a change in eligibility status shortly afterward and was withdrawn from the participant pool before completing baseline questionnaires). As a result, demographic and treatment information is only provided for the four participants who engaged in the treatment and study protocol.

All individuals who expressed interest and/or participated in this study were provided with additional referral sources for individual psychotherapeutic care either at the end of participation or at the study's conclusion.

### **Sample Demographics**

This study had a participant sample of  $N=4$  for individuals who participated in the treatment protocol, all of whom identified as white women with a mean age of 73.75 ( $SD=5.74$ ; min=66, max=79). Three identified as presently married, and one identified as divorced. Of the four participants, three identified a spousal relationship to their care-recipient (husband), and one identified their care-recipient as a parent (mother). One of the four participants identified as employed full-time, two identified as retired, and one identified their occupation as being a full-time caregiver. For education, one participant identified having a high school diploma or GED, one identified some college without a college degree, and two identified having professional degrees. This was consistent with self-reported annual income levels from each participant as well: less than \$20,000 ( $n=1$ ), \$20,000-\$29,999 ( $n=1$ ), and \$100,000-\$124,999 ( $n=2$ ). None of the four participants identified any children under the age of 18 living in the home at the time of this study, and all four identified living with their care-recipient. Regarding the duration of caregiving, two participants identified as being a primary caregiver for less than one year, while the other two identified as providing care to their care-recipient for three-to-five years. Average hours per week spent providing care to their care-recipients across the four participants was 139 hours ( $SD=34.47$  hours, min=100 hours, max=168 hours). None of the four participants identified currently taking any prescribed medication for the management of mental health concerns such as anxiety or depression, nor did any endorse currently ongoing psychotherapeutic treatment for mental health concerns during their participation in this study.

## **Reliability of Measures**

Due to the extremely small sample size within this study ( $N=4$ ), calculating reliability statistics such as Cronbach's alpha ( $\alpha$ ) for the measures included within this study may not have been reliable or appropriate. Prior research suggests that many reliability statistics for psychological assessment measures can be reliably calculated with small samples (i.e., as low as  $N=30$ , Conroy 2016), but it may be difficult to calculate these statistics in a reliable fashion with sample sizes much smaller than 30. In certain instances, the calculation power ( $\beta$ ) can be manipulated (e.g., setting power to  $\beta=.90$  versus  $\beta=.80$ ) to account for variation in total sample size; however, lowering the power of the overall calculation ( $\beta$ ) to account for an extremely small sample size is likely to greatly inflate the risk of type one error (incorrectly rejecting the null hypothesis when the null hypothesis may be true; Bujang et al., 2018). Therefore, to calculate reliability statistics for the measures used within this study as they pertain to this study's sample was not advised due to the results of such calculations likely reflecting significant inflations in type one error rate. As a result, this study relied on the theoretical and empirical reliability and validity of these measures as historically established within the literature (see section, Instruments).

## **Research Question One**

The first and primary research question of interest in this study was pertaining to the overall feasibility of this study and treatment protocol. Specifically, research question one asked whether the manualized group treatment protocol could be implemented in a manner that is feasible for implementation in future pilot/RCT studies. To examine this research question, five separate hypotheses were created to examine separate aspects of feasibility within this study and treatment protocol; each of which are elaborated upon further below.

### ***Hypothesis One***

The first feasibility hypothesis was that the recruitment plan utilized within this study would yield the target number of participants ( $N=15$ ) within a twelve-month period. The method of testing this hypothesis was proposed as a dichotomous goal rather than a statistical null hypothesis test. If the target number of participants was able to be met, then the recruitment plan may have been deemed feasible; however, if the goal could not be met, then the recruitment plan outlined in this study may have been deemed non-feasible. Recruitment rates were also calculated to provide further descriptive information about this recruitment process to further inform future studies.

Across 12-months of continuous direct referral recruitment, only nine individuals contacted the research administrator and expressed interest in this study. Of those nine individuals, seven people were deemed eligible to participate provided consent to participate in the research study. Of the two individuals deemed not eligible to participate, one individual provided a total score of less than 36 on the CBI, and the other reported utilizing full-time respite care services to assist with caregiving duties. As a result, neither of these individuals were deemed eligible given the inclusion/exclusion criteria. Of the seven eligible individuals, one was withdrawn shortly after providing consent to participate due to a change in their eligibility status (care-recipient was enrolled in a long-term care facility, making the caregiver ineligible to participate in this study), and two did not initiate the treatment protocol due to failure of the recruitment plan to yield enough participants to initiate a second arm of data collection/group treatment (see Table 3).



Table 3

## Summary of Recruitment Data

	<i>N</i>
Individuals who expressed interest in participating	9
Individuals screened out (deemed ineligible at time of screening)	2
Score < 36 on Caregiver Burden Inventory (CBI)	1
Utilized > 10 hours/week of respite care services	1
Participants withdrawn after providing consent due to change in eligibility status (care-recipient enrolled in long-term care)	1
Participants who provided consent but could not initiate treatment protocol due to failure of recruitment plan to allow second treatment arm	2
Total participants who provided consent and initiated treatment	4

Using the formula for recruitment rate outlined by Stewart and colleagues (monthly recruitment rate = number of participants recruited / number of months spent recruiting; 2020), the following recruitment-related statistics were calculated: (1) total rate of participants expressing interest in this study ( $9/12=0.75$  participants per month); and (2) total rate of participants deemed eligible and provided consent (including the one individual who was withdrawn due to change in eligibility status post-consent:  $7/12=0.58$  participants per month; this rate drops to  $6/12=0.50$  participants per month excluding the one participant who was withdrawn due to changing eligibility status). This information suggests that if the rate of eligible participants providing consent (0.50-0.58) was maintained at a stable rate, it would take approximately 2.5 years for this study to meet the target recruitment goal of  $N=15$  (likely longer, as recruitment rates are rarely held stable over long periods of time (Lovato et al., 1997; UyBico et al., 2006).

The direct referral source recruitment plan implemented within this study across five different community-based treatment sites yielded a total sample size of  $N=4$  for this study – well below that of the target sample size ( $N=15$ ) desired – and a recruitment rate of approximately 0.50 eligible participants per month. Given this, the recruitment plan as implemented within the context of this study likely cannot be deemed feasible, and the null hypothesis cannot be rejected.

### ***Hypothesis Two***

The second feasibility hypothesis within this study stated that the online CBT group therapy would be able to produce a positive therapeutic climate, as assessed by increased levels of (a) perceived social support, (b) perceived group cohesion, (c) the development of a positive therapeutic alliance, and (d) positive attitudes and engagement towards the group among members from pre-test to post-test. To test this hypothesis, the following measures of group climate were administered to participants after the first group session and again at the end of treatment: Social Provisions Scale (SPS; perceived social support), Therapeutic Factors Inventory cohesion scale (TFI-Coh; group cohesion), Working Alliance Inventory Short Form (WAI-SF; therapeutic alliance), and Group Attitudes Scale (GAS; group engagement). For pre- and post-test statistics of each measure, see Table 4.

Table 4

## Descriptive Statistics, Group Climate Measures

	Baseline		End of Treatment	
	Mean ( <i>SD</i> )	Range (min-max)	Mean ( <i>SD</i> )	Range (min-max)
SPS	66.50 (10.88)	52-78	70.25 (4.03)	67-76
TFI-Coh	40.75 (14.57)	27-57	58.00 (5.29)	51-63
WAI-SF	62.75 (17.23)	38-75	75.75 (12.61)	57-84
GAS	136.75 (34.88)	102-161	163.00 (12.28)	146-172

SPS = Social Provisions Scale; TFI-Coh = Therapeutic Factors Inventory, Cohesion Scale; WAI-SF = Working Alliance Inventory, Short Form; GAS = Group Attitudes Scale

While dependent samples *t*-tests were originally proposed to analyze pre-post treatment differences among group climate metrics, certain assumptions of *t*-test analysis procedures could not be met within the data. While the assumptions of participants appearing in each measurement condition and measures using continuous data were met, the third assumption of dependent variable data points being normally distributed was violated. Skewness and kurtosis metrics were examined in SPSS (Table 5) for baseline and end-of-treatment measurements on each of the group climate scales, and while skewness for each variable was within normal limits ( $<|1.96|$ ; Sheskin, 2011), many kurtosis values were outside of this threshold.

Table 5

## Skewness &amp; Kurtosis Statistics for Group Climate Measures

	Baseline		End of Treatment	
	Skewness	Kurtosis	Skewness	Kurtosis
SPS	-0.77	1.22	1.47	2.03*
TFI-Coh	0.22	-4.37*	-0.86	-0.29
WAI-SF	-1.55	2.15*	-1.90	3.67*
GAS	-0.02	-5.12*	-1.25	0.69

\* denotes values above threshold for normality of |1.96|

SPS = Social Provisions Scale; TFI-Coh = Therapeutic Factors Inventory, Cohesion Scale; WAI-SF = Working Alliance Inventory, Short Form; GAS = Group Attitudes Scale;

In typical situations of normality violations, certain data transformations can be performed to normalize the data and allow it to be analyzed by parametric statistical tests such as the *t*-test. However, given the extremely low sample size of this study ( $N=4$ ) and corresponding low number of data points within each variable, the data may not be reliably transformed without significant manipulation to the data itself, making analyses with the small-sample data potentially unreliable or inaccurate. Therefore, it would be more appropriate to use a nonparametric statistical test which can account for non-normality among the dependent variables (Maxwell & Delaney, 2004). The Wilcoxon Signed-Rank test would provide the best alternative to analyzing this data, as it is able to assess for statistically significant differences between two points of measurements administered at different time intervals without being constrained by the assumption of normality among the dependent variable data points (Maxwell & Delaney, 2004).

Four separate Wilcoxon Signed-Rank tests were performed to assess for changes in pre-to-post treatment differences among each of the four group climate metrics. Because each of these four statistical analyses were considered to be within the same family of measurement

(group climate), type one error ( $\alpha$ ) was corrected to prevent familywise error inflation using Bonferroni's  $\alpha$  correction formula:  $\alpha_{PC} = \alpha/C$ , where  $\alpha = .05$  and  $C$  = number of comparisons (Maxwell & Delaney, 2004). The resulting alpha per comparison ( $\alpha_{PC}$ ) was determined as such:  $\alpha_{PC} = 0.05/4 = 0.0125$ . Results are displayed in Table 6 below, with figures 1-4 depicting the scatter of data points from baseline to end of treatment.

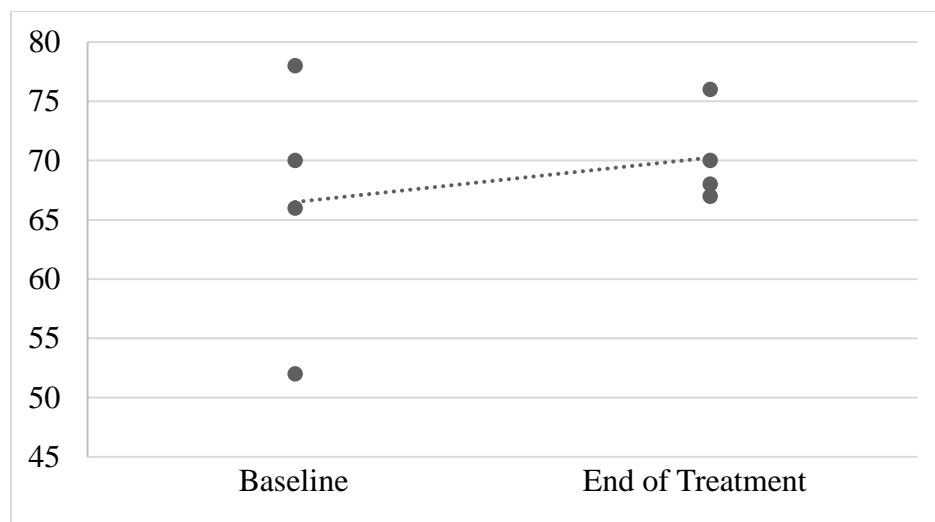
Table 6

## Wilcoxon Signed-Rank Test Results, Group Climate Measures

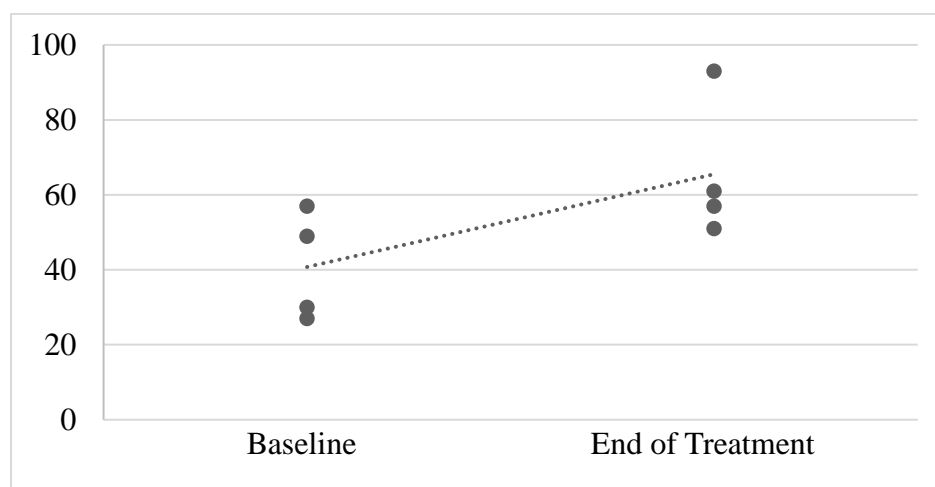
Group Climate Variable (measure)	<i>Z</i>	<i>Md</i> Pre	<i>Md</i> Post	<i>r</i>
Perceived Social Support (SPS)	-0.73	68.00	69.00	-0.258
Perceived Group Cohesion (TFI-Coh)	-1.83	39.50	59.00	-0.647
Positive Therapeutic Alliance (WAI-SF)	-1.83	69.00	81.00	-0.647
Group Engagement (GAS)	-1.60	136.50	167.00	-0.566

\* denotes statistical significance at corrected  $p = .0125$

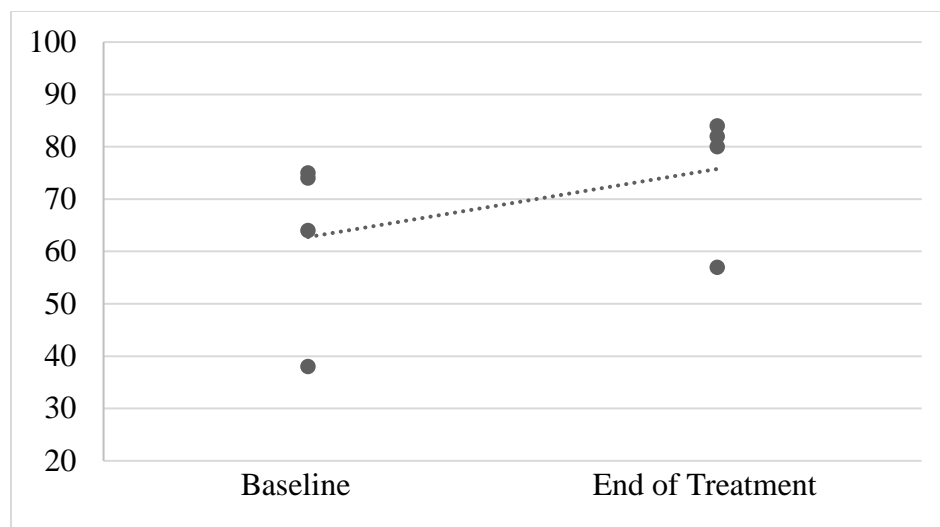
*Md* = median; SPS = Social Provisions Scale; TFI-Coh = Therapeutic Factors Inventory, Cohesion Scale; WAI-SF = Working Alliance Inventory, Short Form; GAS = Group Attitudes Scale



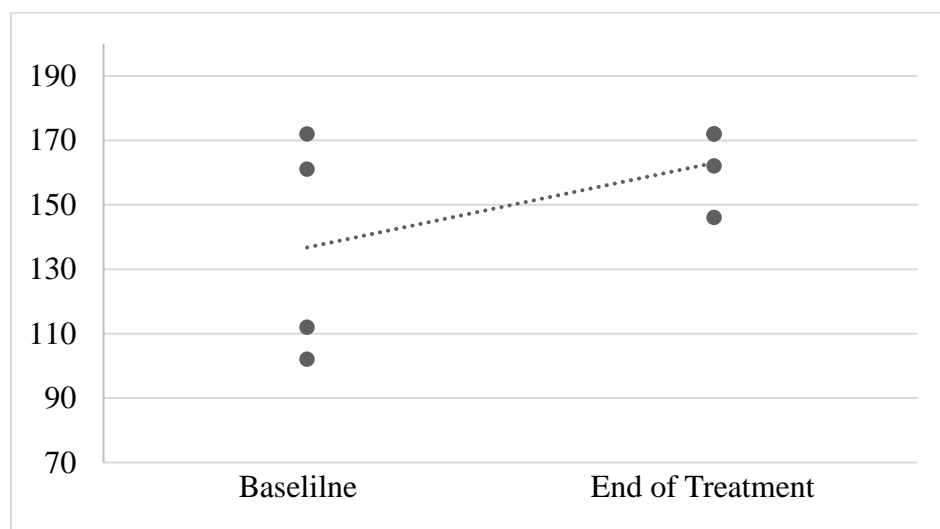
*Figure 1.* Social Provisions Scale (SPS), baseline to end of treatment scatterplot



*Figure 2.* Therapeutic Factors Inventory Cohesion Scale (TFI-Coh), baseline to end of treatment scatterplot



*Figure 3.* Working Alliance Inventory Short Form (WAI-SF), baseline to end of treatment scatterplot



*Figure 4.* Group Attitudes Scale (GAS), baseline to end of treatment scatterplot

Based on these results, none of the four measures of group climate (perceived social support, perceived group cohesion, positive therapeutic alliance, and group engagement)

experienced significant changes across the eight-week treatment protocol. While three out of four group climate metrics (cohesion, therapeutic alliance, and engagement) were considered to have strong effect sizes ( $r > .50$ ; Cohen, 1988), these effects were not deemed statistically significant. However, upon closer examination of median differences in each variable from pre- to post-treatment time-points ( $\Delta$ SPS=1.00;  $\Delta$ TFI-Coh=19.50;  $\Delta$ WAI-SF=12.00;  $\Delta$ GAS=31.00), it is possible that some of these change scores may represent clinically significant change even if they are not found to be statistically significant.

One measure of clinically significant change (as outlined by Mann and colleagues, 2012) is to examine whether or not the change score exceeds  $\pm$  two standard deviations from a mean derived from a normative or validation sample or other large-sample research study, as this would likely be representative of change that is clinically meaningful even if it is not found to be statistically significant. In returning to the literature surrounding the validation of each individual measure, the following criteria for clinically significant change were determined:  $|\Delta$ SPS|  $> 19.78$  (Cutrona & Russell, 1987),  $|\Delta$ TFI-Coh|  $> 15.12$  (Lese & MacNair-Semands, 2000),  $|\Delta$ WAI-SF|  $> 23.74$  (Marziliano et al., 2021), and  $|\Delta$ GAS|  $> 31.68$  (Pisetsky et al., 2015). Using these empirically informed cut-off scores, clinically significant change was noted in group cohesion from start-to-end of treatment (with  $\Delta$ TFI-Coh = 19.50). Perceived social support, working alliance, and group engagement scores did not demonstrate clinically significant change across treatment time. Therefore, while the null hypothesis for statistically significant change cannot be rejected, results may warrant further investigation for clinically significant change.

### ***Hypothesis Three***

The third feasibility hypothesis within this study stated that the study would maintain adequate participant retention. Retention in this study was operationalized as participants



completing the entire course of treatment (i.e., eight weeks) without withdrawing or otherwise self-discontinuing from the research study. There were no participants who initiated treatment and were withdrawn by the research administrator. For this hypothesis, the target for adequate retention was set at 80% retention (i.e., less than 20% attrition). This number was determined based on review of multiple meta-analytical studies of group therapy for varying psychological presenting concerns, across which the average attrition (drop-out) rates ranged from 15-28% (with some variable for presenting concerns; Dixon & Linardon, 2019; Hans & Hiller, 2013a; Hans & Hiller, 2013b; Imel et al., 2013; Ong et al., 2018).

In this study, retention was calculated as follows:  $ret = (x/N_a) * 100$ , where  $x$  = total number of participants who complete the eight-week treatment protocol and  $N_a$  = the total number of participants who enrolled and began treatment. Attrition, being the inverse of retention, was then calculated as follows:  $[1 - (x/N_a)] * 100$ . Of the four participants who consented and began the eight-week treatment protocol, all four completed all eight weeks of intervention, leading to a 100% retention rate and 0% attrition rate. Therefore, the null hypothesis can be rejected; however, it should be done with caution due to the extremely low sample size of this study.

#### ***Hypothesis Four***

The fourth feasibility hypothesis in this study stated that the online CBT group therapy protocol would produce positive levels of satisfaction towards the therapy among group members, as assessed at post-treatment. To test this hypothesis, descriptive analyses in SPSS on each item of the STTS-R (including item 13 which is a stand-alone measure of perceived treatment benefit) as well as total satisfaction with therapy and therapist subscales were performed and can be seen in Table 7 below.

Table 7

## Descriptive Statistics, STTS-R Items and Scales

	N	Mean	SD
(1) I am satisfied with the quality of therapy I received.	4	4.50	0.58
(2) The therapist listened to what I was trying to get across.	4	5.00	0.00
(3) My needs were met by the program.	4	4.50	1.00
(4) The therapist provided an adequate explanation regarding my therapy.	4	4.75	0.50
(5) I would recommend the program to a friend.	4	4.75	0.50
(6) The therapist was not negative or critical towards me.	4	4.25	0.50
(7) I would return to the clinic if I needed help.	4	4.00	0.82
(8) The therapist was friendly and warm towards me.	4	5.00	0.00
(9) I am now able to deal more effectively with my problems.	4	4.50	0.58
(10) I felt free to express myself.	4	4.75	0.50
(11) I was able to focus on what was of real concern to me.	4	4.50	0.58
(12) The therapist seemed to understand what I was thinking and feeling.	4	4.50	0.58
(13*) How much did this treatment help with the specific problem that led you to therapy?	4	4.00	1.41
(Subscale) Satisfaction with Therapy	4	26.75	3.59
(Subscale) Satisfaction with Therapist	4	28.25	0.96

Note: Questions 1-12 are scored on a likert-scale 1-5, with 1 = strongly disagree and 5 = *strongly agree*. Question 13 is a stand-alone item scored on a likert-scale 1-5, with 1 = *made things a lot worse* and 5 = *made things a lot better*. The Satisfaction with Therapy subscale is calculated by the sum of all odd-numbered items excluding item 13. The Satisfaction with Therapist subscale is calculated by the sum of all even-numbered items. Both subscales can range in values from 6-30, with higher scores indicating higher levels of satisfaction.

Based on the results displayed in Table 7 above, members appeared to report high to very-high levels of satisfaction on average at the end of the group treatment protocol. Upon examining individual item responses, zero participants provided a rating of either 1 (*strongly disagree*) or 2 (*disagree*) to any of items 1-12; only two items (items 3 and 7) received one response of 3 (*neutral*), with all other responses on items 1-12 being notably positive (i.e., 4=*agree* or 5=*strongly agree*). In examining item 13, a stand-alone item assessing for subjective levels of treatment progress, one member reported that the group therapy protocol “made things

somewhat worse” ( $n=1$ ); one member reported that being in the group “made things somewhat better” ( $n=1$ ); and two members reported it “made things a lot better” ( $n=2$ ). In examining the satisfaction with therapy and therapist subscales, average ratings indicate very high levels of satisfaction in each domain (satisfaction with therapy mean = 26.75, min = 22, max = 30; satisfaction with therapist mean = 28.25, min = 27, max = 29).

Additionally, each participant had an opportunity to provide information in an open-ended format regarding their experiences and overall satisfaction as a participant in this study. Of the four participants, three provided open-ended qualitative feedback to this item. All three members who provided responses reported general levels of satisfaction, with frequent key words including “gratifying,” “helpful,” and “satisfying.” In describing the therapist, the following key phrases were noted across two of the three open responses: “sincere,” “caring,” “helpful,” “welcoming,” and “good listener.” Additionally, two of the three responses provided included statements which expressed appreciation and thanks to the therapist. One of the three members who provided an open response indicated a wish for the group to be longer in session duration (i.e., greater than one hour/week) and number of sessions.

Given the above information, participants on the whole reported high to very-high levels of satisfaction towards this treatment protocol. On average, participants reported that the treatment protocol was helpful. Therefore, the null hypothesis may be rejected; however, it should be done with caution given the low sample size and limited statistical power within this study.

### ***Hypothesis Five***

The fifth feasibility hypothesis in this study stated that the intervention protocol would not create significant levels of perceived burdensomeness among participants. In this study,

burdensomeness was operationally defined as a level of effort and energy expenditure as a result of participation that in turn increases participants' level of reported distress (Lingler et al., 2014). To measure perceived levels of research burdensomeness, the mPRBA was administered to each participant at the end of the treatment protocol. While the PRBA was originally designed to be implemented at the start of a research study to assess projected perceived burdensomeness towards participating in a study, the authors of the measure note that it can be modified and adapted into past tense (rather than future tense) to assess post-hoc perceived burdensomeness after participation in a study is complete (mPRBA; Lingler et al., 2014). Descriptive statistics of the scores from the mPRBA administered at post-treatment can be seen in Table 8 below.

Table 8

## Descriptive Statistics, mPRBA

	N	Mean	Min	Max	SD
Total Burden Ratings	4	18.75	17	23	2.87
Psychological Burden subscale	4	7.25	7	8	0.50
Logistical Burden subscale	4	10.50	9	15	3.00
Physical Burden subscale	4	1.00	1	1	0.00

Note: items are scored on a likert-scale of 1-5, with 1 = strongly disagree and 5 = strongly agree. As a result, the minimum and maximum scores for each subscale of the mPRBA are as follows: Total Burden (16-80), Psychological Burden (7-35), and Logistical Burden (9-45). The physical burden subscale is measured by a stand-alone item (#12), and therefore has a possible range of 1-5. In all instances, lower scores indicate lower levels of burden.

In examining descriptive statistics of the mPRBA (Table 8 above), participants in this study on the whole reported low levels of research burden across all domains of burden assessed, including psychological burden (perceived levels of distress caused by participating in a research

study), logistical burden (study accessibility, cost-effectiveness, or time-involvement), and physical burden (overall desire to have remained in the study). In examining the total burden levels, participants reported an average total burden rating of 18.75 (min=17, max=23), which is below the authors' suggested cut-off for elevated levels of perceived research burden (30; Lingler et al., 2014). Therefore, these results suggest that the null hypothesis can be rejected in this case; however, rejection of the null hypothesis should be done with caution given the extremely low sample size and number of data points.

### **Research Question Two**

The second, exploratory research question of this study asked whether the treatment protocol could produce significant reductions in overall levels of caregiver burden, anxious symptoms, depressive symptoms, and levels of role captivity among participants. Even with the understanding that feasibility studies often operate from a stance of low statistical power and limited efficacy (Bowen et al., 2009; Freeland, 2016; Orsmond & Cohn, 2015; Tickle-Degnen, 2013), it was still important to observe any potential changes in symptom-based measures as a means of informing future pilot/RCT studies.

### ***Hypothesis Six***

The exploratory sixth hypothesis of this study, stemming from research question two, was that the treatment protocol would reduce levels of (a) caregiver burden, (b) depressive symptoms, (c) anxious symptoms, and (d) role captivity across treatment. While assessments were administered at three separate time-intervals throughout treatment (baseline, after session 4/mid-treatment, and end-of-treatment), it likely was not appropriate to examine all three time point intervals using an ANOVA-based ( $F$ -test) design due to significantly low levels of projected power resulting from this study's unexpectedly small sample size ( $N=4$ ). As a result, it

was likely more appropriate to examine only pre- to post-treatment differences in each of the outcome measures to reduce the strain of low statistical power (Maxwell & Delaney, 2004).

Regardless, descriptive statistics are still reported here for each outcome measure at each measurement time-point in Table 9 below.

Table 9

Descriptive Statistics, Symptom and Outcome Measures

	Baseline		Mid-Treatment		End of Treatment	
	Mean (SD)	Range (min-max)	Mean (SD)	Range (min-max)	Mean (SD)	Range (min-max)
CBI	46.50 (11.62)	36-58	32.25 (17.90)	15-56	27.75 (12.82)	21-47
HADS-A	9.00 (2.94)	6-12	8.25 (1.26)	7-10	9.00 (3.37)	4-11
HADS-D	5.75 (3.10)	3-10	5.00 (2.94)	2-8	4.00 (2.71)	0-6
RCS	6.00 (2.16)	3-8	5.75 (1.89)	3-7	5.25 (2.06)	3-8

CBI = Caregiver Burden Inventory; HADS-A = Hospital Anxiety and Depression Scale, anxiety subscale; HADS-D = Hospital Anxiety and Depression Scale, depression subscale; RCS = Role Captivity Scale

While a set of parametric dependent samples *t*-tests would be the initial choice of statistical procedures to examine pre-post differences in these measures, certain assumptions of *t*-test analysis procedures could not be met within the data. While the assumptions of participants appearing in each measurement condition and measures using continuous data were met, the third assumption of dependent variable data points being normally distributed was violated. Skewness and kurtosis metrics were examined in SPSS (Table 10) for baseline and end-of-treatment measurements on each of the outcome measure variables; the results showed multiple violations of skewness and kurtosis (i.e.,  $>|1.96|$ ; Sheskin 2011).

Table 10

Skewness and Kurtosis Values for Outcome Measures, Pre- and Post-Treatment

	Baseline		End of Treatment	
	Skewness	Kurtosis	Skewness	Kurtosis
CBI	0.51	-5.63*	1.99*	3.97*
HADS-A	0.00	-4.89*	-1.89	3.58*
HADS-D	1.14	0.76	-1.81	3.48*
RCS	-1.19	1.50	0.71	1.76

\* denotes values above threshold for normality of |1.96|

CBI = Caregiver Burden Inventory; HADS-A = Hospital Anxiety and Depression Scale, anxiety subscale; HADS-D = Hospital Anxiety and Depression Scale, depression subscale; RCS = Role Captivity Scale

Similar to the procedures for hypothesis two delineated previously, in which the assumption of normality was violated, it was believed to be not ideal to perform certain data transformations to normalize the data due to the significantly low sample size of this study ( $N=4$ ), as to do so may have introduced significant bias within the data and render results unreliable (Maxwell & Delaney, 2004). Therefore, it was deemed more appropriate to use a nonparametric statistical test which could account for non-normality among the dependent variables, such as the Wilcoxon Signed-Rank test (Maxwell & Delaney, 2004).

Four separate Wilcoxon Signed-Rank tests were performed, one for each dependent variable (caregiver burden, depressive symptoms, anxious symptoms, and role captivity). Because each outcome variable can be treated as its own family of statistical procedures, alpha correction was not needed unless further follow-up analyses were deemed necessary within each outcome measure (Maxwell & Delaney, 2004). The results of these analyses can be seen in Table 11 below, with figures 5-8 depicting the scatter of data from baseline to end of treatment.

Table 11

Wilcoxon Signed-Rank Test Results, Outcome Measures

Group Climate Variable (measure)	<i>Z</i>	<i>Md</i> Pre	<i>Md</i> Post	<i>r</i>
Caregiver Burden (CBI)	-1.83	46.00	21.5	-.647
Anxious Symptoms (HADS)	0.00	9.00	10.50	.000
Depressive Symptoms (HADS)	-1.10	5.00	5.00	-.389
Role Captivity (RCS)	-0.82	6.50	5.00	-.290

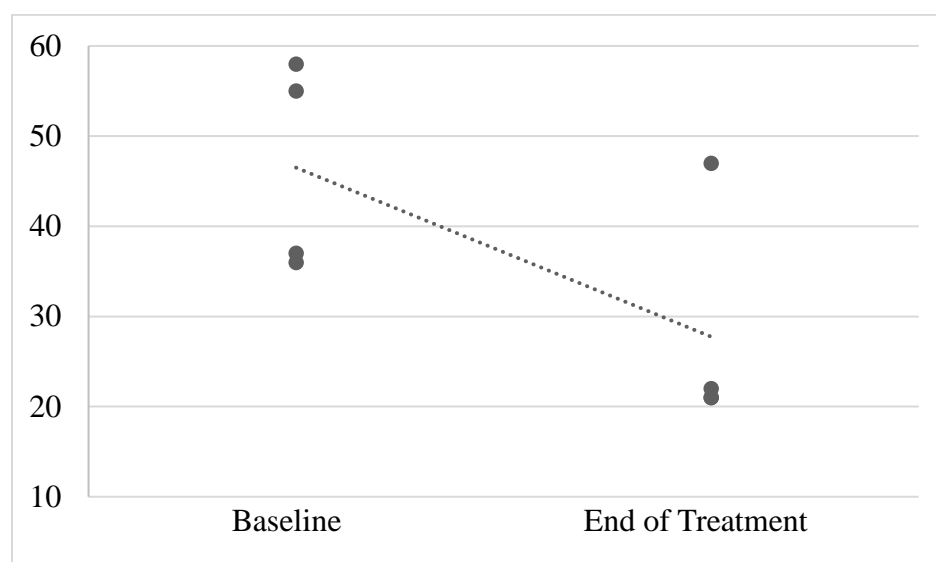
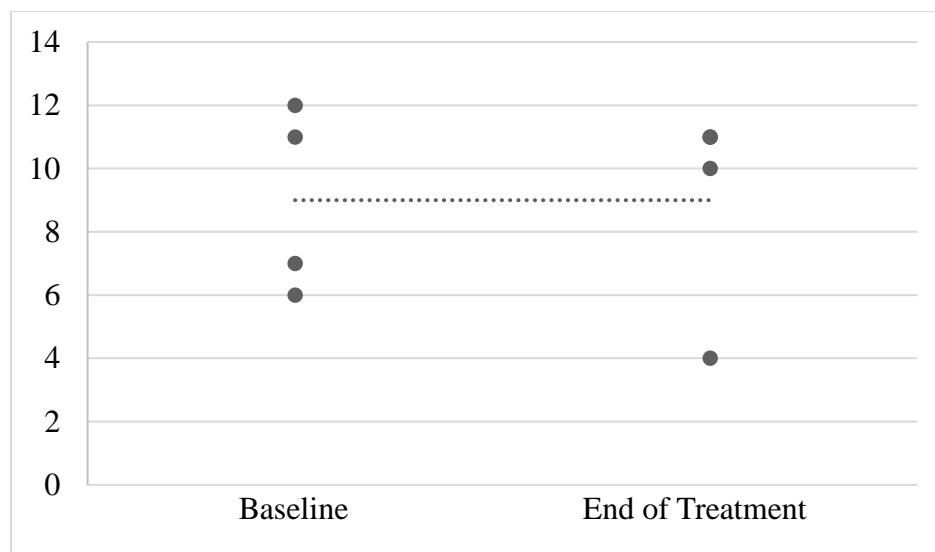
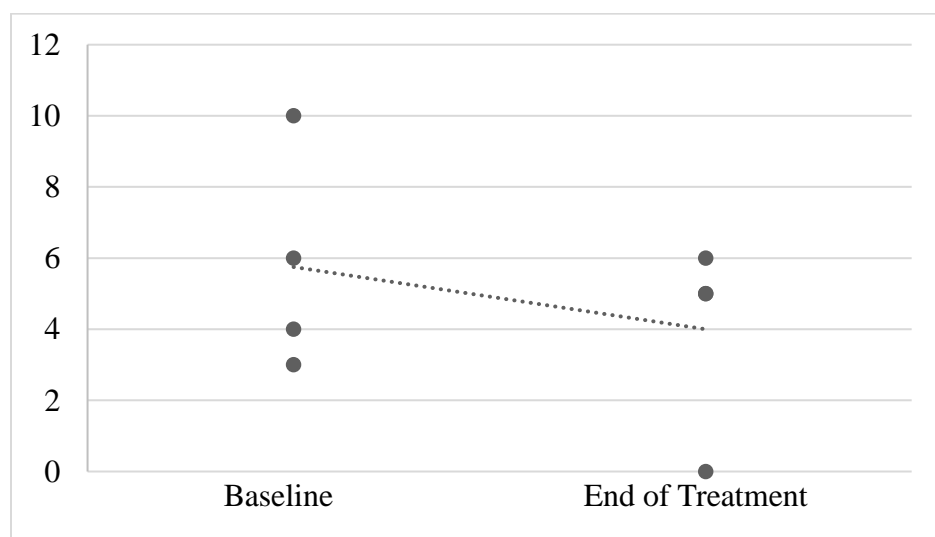
\*  $p < .05$ ; \*\*  $p < .01$ ;  $p < .001$ *Md* = median; CBI = Caregiver Burden Inventory; HADS = Hospital Anxiety and Depression Scale; RCS = Role Captivity Scale

Figure 5. Caregiver Burden Inventory (CBI), baseline to end of treatment scatterplot





*Figure 6.* Hospital Anxiety and Depression Scale anxiety subscale (HADS-A), baseline to end of treatment scatterplot



*Figure 7.* Hospital Anxiety and Depression Scale depression subscale (HADS-D), baseline to end of treatment scatterplot

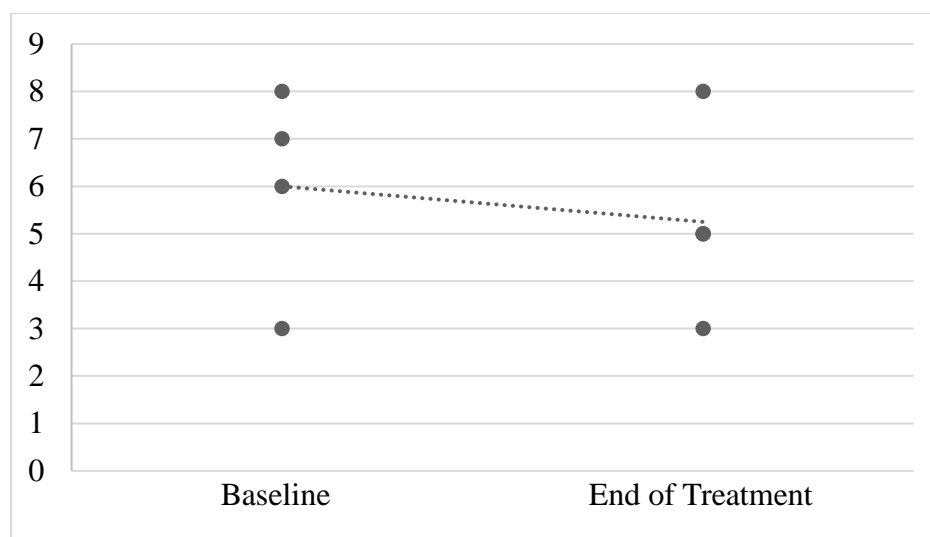


Figure 8. Role Captivity Scale (RCS), baseline to end of treatment scatterplot

Based on these results, none of the four outcome variables (caregiver burden, anxious symptoms, depressive symptoms, and role captivity) experienced significant changes across the eight-week treatment protocol. While effect sizes ranged in weight, including null (anxious symptoms), small (role captivity and depressive symptoms), and large (caregiver burden; Cohen, 1988), these effects were not deemed statistically significant. However, upon closer examination of the median differences in each variable from pre- to post-treatment time-points ( $\Delta$ CBI=-24.50;  $\Delta$ HADS anxious symptoms=1.50;  $\Delta$ HADS depressive symptoms=0.00;  $\Delta$ RCS=-1.50), it is possible that some of these changes may represent clinically significant changes even if they are not found to be statistically significant.

Using the method outlined by Mann and colleagues (2012) of change  $> \pm$  two standard deviations from a mean derived from a normative or sample or other large-study research reportings, the following cut-off scores for clinical significance were determined for each variable:  $|\Delta$ CBI|  $> 22.90$  (D'Onofrio et al., 2014),  $|\Delta$ HADS anxious symptoms|  $> 7.68$  (Johnston et al., 2000),  $|\Delta$ HADS depressive symptoms|  $> 6.14$  (Johnston et al., 2000), and  $|\Delta$ RCS|  $> 4.86$

(Givens et al., 2013). Using these empirically informed cut-off scores, clinically significant change was noted across caregiver burden scores from start-to-end of treatment ( $\Delta$ CBI=-24.50). Anxious symptoms, depressive symptoms, and role captivity scores did not demonstrate clinically significant change across treatment time. Therefore, while the null hypothesis for statistically significant change cannot be rejected, results may warrant further investigation for clinically significant change.

## CHAPTER IV

### DISCUSSION

Caregiver burden, as defined as “the overall impact of the physical, psychological, social, and financial demands of caregiving” (Mavardi et al., 2005, p. 46), is a condition that often arises within the context of providing care to a family member with a chronic illness such as dementia (Adelman et al., 2014). Individuals who provide care and who concurrently experience caregiver burden are at greater risk for declining physical health, psychological health, and overall quality of life (Limpawattana et al., 2012). With rates of dementia increasing exponentially around the world (Alexopolous & Kelly, 2009; Alzheimer’s Association 2016; Kelly & Petersen, 2007; NIA et al., 2015; Rabey & Dobrenovsky, 2016; Saykin & Rabin, 2014; WHO, 2015), and with rates of at-home provision of care for persons with dementia increasing as well (Alzheimer’s Association, 2018; Black et al., 2013), rates of caregiver burden among primary family caregivers of persons with dementia are also on-the-rise (Adelman et al., 2014).

While interventions and support services for caregiver burden do exist, empirical exploration of these interventions have found them to be, on the whole, historically ineffective or inaccessible. There are a number of hypothesized reasons for these low effect sizes, the most notable of which being because caregiver burden is a multi-component issue, comprised of many concerns and factors such as time-related demands, financial demands, physical strain, emotional strain, familial/relational strain, and more (Acton & Kang, 2001; Marvardi et al., 2005), while many of the common interventions for caregiver burden are single-component in nature and do not take into consideration the intersectionality of the problem.

It was the primary aim of this study to propose a new intervention that is multi-component in nature, theoretically informed, and accessible to primary family caregivers of

persons with dementia and who may be experiencing caregiver burden, and to test the feasibility of this multi-component, online, cognitive behavioral, group-based intervention. Based on the current body of research, six hypotheses were created, the first five of which directly related to the feasibility of this intervention and research protocol: (1) a recruitment plan utilizing a direct referral process will yield the target number of participants desired ( $N=15$ ) within a 12-month period; (2) the online CBT group-based protocol will produce a positive therapeutic climate; (3) the study and intervention protocol will maintain adequate participant retention ( $>80\%$ ); (4) the CBT group therapy protocol will produce positive levels of satisfaction among participants; (5) the intervention and research protocol will not produce significant levels of perceived burdensomeness among participants; and (6) the treatment protocol will significantly reduce levels of caregiver burden, anxious and depressive symptoms, and role captivity.

The results of this study were generally null-to-mixed, indicating that there may be areas in which this treatment and research protocol may be feasible, and other areas in which feasibility may be more questionable. Of particular concern within this study was the recruitment of participants. While feasibility studies often operate from stances of diminished power and limited efficacy (Bowen et al., 2009; Freeland, 2016; Orsmond & Cohn, 2015; Tickle-Degnen, 2013), the extremely small sample size of this study ( $N=4$ ) poses a significant challenge not only for power, but also for determining other aspects of feasibility, as such a low sample size likely calls all results into question. Additionally, with extremely small sample sizes such as this, the presence of outliers is very likely to skew the data, making interpretations unreliable (Maxwell & Delaney, 2004). Therefore, while the data in this study may suggest potential areas of feasibility, no firm statements can be made about feasibility at this time due to low recruitment, thus rendering these results inconclusive.

While direct referral recruitment strategies have been identified as feasible recruitment plans in prior clinical research studies (Greenfield et al., 2014), it is clear that the recruitment strategy utilized within this study protocol was unsuccessful and therefore cannot be deemed feasible. This could be for a number of potential reasons, including the presence of an ongoing global pandemic (e.g., novel coronavirus disease 2019; COVID-19), or the potential non-applicability of an online intervention for the target population. Multiple researchers have highlighted recruitment difficulties in clinical research studies across various domains of research as a direct result of the COVID-19 pandemic (Gertner, 2020; Magan et al., 2020; Mirza et al., 2021; Park et al., 2021; Peeters et al., 2020; Richardson et al., 2020; Sathian et al., 2020; Stilles-Shields et al., 2020; Strujo et al., 2020). Specifically, these authors have noted trends around difficulty meeting recruitment goals, needing to expand recruitment procedures, placing temporary or indefinite holds on recruitment procedures, needing to extend research timelines to meet recruitment goals, and a recurring pattern of under-recruitment believed to be a direct result of the COVID-19 pandemic and the strains it has placed on research infrastructure around the world and across disciplines (e.g., concerns around conducting research safely in-person, need to reduce medical visits, need to prioritize recruitment for studies related to COVID-19, difficulties transitioning in-person research to online modalities, diminished accessibility of research to participant populations, fear around the pandemic, and more). Furthermore, it is worth noting that the recruitment liaison for the three Sentara Neuropsychological Specialists recruitment sites (Norfolk, VA; Virginia Beach, VA; Hampton, VA) reported an overall decrease in the number of senior adults seeking services during the course of the study related to the COVID-19 pandemic at each location. While fewer senior adults sought in-person services, the liaison also noted difficulties with telehealth service access due to frequent difficulties with telehealth procedures

for this population (B. Gilstrap, personal communication, December 11, 2020). While this study sought to recruit family caregivers, and not the identified individual diagnosed with dementia, prospective participants were identified through office visits (in-person or telehealth) for the care-recipient. Therefore, this likely marks a reduction in access to the target population for this study due to the COVID-19 pandemic.

Additionally, qualitative data gathered during this study indicates that the online modality of the intervention protocol may have been less ideal for the target population (family caregivers of persons with dementia). Throughout the course of the treatment sessions, three of the four participants explicitly expressed difficulty or concerns about finding a private space in their home away from their care-recipient or finding alternative care for their care-recipient during the one-hour treatment session each week. As a result, the same three-of-four participants agreed that it would have been easier to access group treatment if it were not taking place remotely or in their homes (the remaining fourth participant was able to make arrangements to attend group sessions from a private space in their work location, but stated they would not have been able to participate if the treatment sessions took place at any different time of the day). Additionally, three-of-four participants had to step away from the group session at least once throughout the course of treatment due to concerns arising with their care-recipient (e.g., care-recipient entered the room, care-recipient needed care/assistance during the group session). During the recruitment process, the two participants who provided consent but did not initiate treatment due to failure to launch a second treatment arm also expressed concern and worry about finding a private space while at home once the prospective group would have started; both made requests and asked if the group could be held in-person rather than online.

All of these concerns are potential explanations as to why the recruitment goal was not met despite using a recruitment plan deemed feasible in prior research studies. Therefore, while the recruitment plan utilized here was deemed not feasible for this study, further exploration into this study's research questions and potential adaptations of recruitment plan is certainly warranted.

Regarding the second hypothesis of therapeutic climate, none of the four group climate measures noted statistically significant change from start-to-end of treatment, indicating that this online group protocol was unable to produce statistically significant changes in therapeutic climate variables such as perceived social support, group cohesion, therapeutic working alliance, or group engagement. However, these results should be interpreted with caution due to the extremely low sample size and resulting low statistical power within this study. Additionally, using criteria developed by Mann and colleagues (2012) for quantifying clinically significant change, perceived group cohesion scores, as measured by the TFI-Coh, demonstrated clinically significant change from start-to-end of treatment, with  $\Delta$ TFI-Coh=19.50 ( $> 15.12$ ). While the other group climate metrics did not demonstrate clinically significant change, these results may warrant further investigation into the feasibility of this research and treatment protocol in creating a clinically meaningful therapeutic group climate.

Regarding the third feasibility hypothesis, this study did demonstrate adequate retention of participants who initiated treatment above the empirically informed cut-off of 80% (study retention = 100%). It is possible that the clinically significant change in group cohesion may have contributed to the high level of participant retention (as suggested by Yalom & Leszcz, 2005). However, these results should be interpreted with caution, and generalization of these



retention results to other research studies is not recommended at this time due to the extremely low sample size within this study rendering these results ultimately inconclusive.

Regarding feasibility hypothesis four, participants appeared to report generally high levels of satisfaction within the group treatment protocol, with satisfaction ratings being on-the-whole positive in nature. Additionally, participants generally reported the treatment program as subjectively beneficial to them. However, it should be noted that while the data from this study may suggest high satisfaction levels, no firm statements about participant satisfaction can be drawn or applied to individuals or samples outside of this study. While the data may warrant further investigation of this treatment protocol, the results are ultimately inconclusive.

Regarding the fifth feasibility hypothesis, results indicated that participants experienced low levels of burden as a result of the research procedures, with the total perceived burden scale average score (18.75) being below the empirically informed cut-off of 30 for elevated levels of research burden (Lingler et al., 2014), and individual sub-scale scores representing near-minimum burden scores. Therefore, the data gathered from this study indicate that the research and intervention procedures included in this study produce relatively low levels of additional burden on those who engage with it. Again, though, extrapolation of these results to participants or samples outside of this study is not recommended, as the extremely low sample size renders these results inconclusive.

Lastly, regarding the exploratory sixth hypothesis, none of the four outcome variables demonstrated statistically significant change from start-to-end of treatment, indicating that this online group treatment protocol was unable to produce significant changes in symptom-based or other outcome measures included in this study such as caregiver burden, anxious symptoms,

depressive symptoms, or role captivity. However, these results should be interpreted with caution due to the extremely low sample size and resulting low statistical power within this study.

Additionally, using criteria developed by Mann and colleagues (2012) for quantifying clinically significant change, caregiver burden ratings (the primary outcome measure of this exploratory research question and ultimate target of the intervention protocol) demonstrated clinically significant change from start-to-end of treatment, with  $\Delta\text{CBI} = -24.50$  (the absolute value of which is greater than the cut-off of 22.90). While the other exploratory outcome variables (anxious symptoms, depressive symptoms, and role captivity) did not demonstrate clinically significant change, these results do pose potential evidence to warrant further investigation into this treatment protocol for the reduction of caregiver burden in future studies (after further support for feasibility of the treatment protocol has been demonstrated).

Additionally, it is important to note that the results of clinical significance are somewhat surprising. Historically, studies examining interventions for caregiver burden have found relatively little changes in overall caregiver burden ratings, while other – more specific – outcome measures of frequent comorbidities (such as anxious and depressive symptoms) were more likely to demonstrate statistical and clinical change (Acton & Kang, 2001). This is believed to be related to the multi-dimensional nature of caregiver burden, leading many single-component interventions to produce reductions in targeted areas of distress (e.g., depressive or anxious symptoms) without globally targeting caregiver burden as a whole. It is possible that the multi-dimensional nature of this intervention protocol allowed for a more specified treatment of caregiver burden rather than associated comorbidities. Additionally, the intervention protocol was developed based on a theoretically informed conceptualization of caregiver burden rather than associated comorbidities such as anxious or depressive symptoms. This, in conjunction with

the results of clinically significant change in caregiver burden, may indicate that this treatment protocol is more specified and targeted for reducing caregiver burden, and may not be entirely appropriate to treat depressive or anxious symptoms specifically. However, it is important to note that the extremely low sample size and resulting limited statistical power within this study ultimately renders these results inconclusive. While the data from this study may suggest these conclusions, these statements cannot be generalized outside the bounds of this present study, with further research on this protocol's feasibility being required. Results and conclusions drawn from this study's data should not be generalized to other research studies (and especially clinical settings) until further feasibility data has been collected.

### **Limitations & Future Considerations**

The major limitation of this study is the extremely low sample size ( $N=4$ ). Because the recruitment plan was not deemed feasible to recruit the target sample size ( $N=15$ ), much of the results in this study are not reliable or generalizable. While feasibility studies such as this are known to operate from positions of reduced statistical power (Bowen et al., 2009; Freeland, 2016; Orsmond & Cohn, 2015; Tickle-Degnen, 2013), a sample size of  $N=4$  certainly brings the statistical power of the above results into question. Despite this fact, it is important to note that the primary objective of this study was not to demonstrate preliminary feasibility such as a pilot or pilot-RCT study; the primary purpose of this study was to attempt to demonstrate preliminary feasibility for the multi-component, cognitive behavioral, online, group-based therapy for caregiver burden. While this objective can be accomplished with limited statistical power (Bowen et al., 2009; Freeland, 2016; Orsmond & Cohn, 2015; Tickle-Degnen, 2013), the small sample size present within this study may provide a limitation above and beyond that which is typically seen in feasibility studies. That being said, while these results do warrant cautious

interpretation as to the feasibility of this treatment protocol, the results do demonstrate evidence in support of continued examination of its feasibility in future feasibility-oriented studies.

A major influence on the small sample size in this study, as noted previously, may be the presence of the COVID-19 pandemic actively ongoing throughout the course of this study's recruitment and data collection procedures. It has previously been noted that the COVID-19 pandemic has significantly and negatively impacted many clinical research studies across psychological and medical fields of study (Gertner, 2020; Magan et al., 2020; Mirza et al., 2021; Park et al., 2021; Peeters et al., 2020; Richardson et al., 2020; Sathian et al., 2020; Stilles-Shields et al., 2020; Strujo et al., 2020). While this is not a limitation that could be controlled within this study, it is important to note nonetheless that the presence of a global pandemic during the course of this study not only likely impacted the data collection procedures but may also impact generalizability of the results. Because all interventions and data collection procedures took place during the pandemic, it is unclear how these feasibility results may generalize to future studies seeking to explore these topics further after the end of a global pandemic. Therefore, it is safe to say that the presence of the COVID-19 pandemic during the course of this study may pose a second limitation in and of itself in the generalization of these results to future studies.

A third limitation, and related to the limited sample size, is the limited representation of diverse populations and cultural groups within this study's sample. As previously mentioned, all four participants who engaged in the treatment protocol identified as white women between the ages of 66 and 79 years old. While certain aspects of these demographics may be rather common in the dementia caregiver population, with approximately 66% of caregivers identifying as women and 34% being age 65 or older (CDC, 2019), the sample within this study failed to represent many other important demographic aspects of dementia caregiving. Demographic

studies have shown that 39% of family caregivers identify as daughters of the care-recipient, followed by 25% spouses, 17% sons, and 20% other family and friends (Mather & Scommegna, 2020). It is also noted that people diagnosed with dementia and who are of a racial/ethnic minority status are more likely to receive care at home than non-Hispanic white individuals (PRB, 2020). Additionally, while this is present among clinical research of most scientific backgrounds, research in Alzheimer's disease, dementia, and dementia caregiving tends to be racially/ethnically biased in favor of non-Hispanic white populations, leading to pervasive patterns of distrust among black, indigenous, and people of color (BIPOC), and other minority groups in the United States towards dementia-related healthcare and research (Alzheimer's Association, 2021). As a result, the lack of cultural, racial, and ethnic diversity in this sample does pose a significant problem, in that the use and generalization of these results without careful consideration of lack of diversity factors may further contribute to the issue of inclusivity (or lack thereof) within this particular field of research. It is strongly recommended that any future studies examining the feasibility of this treatment protocol seek to include a diverse sample pool to both ensure inclusivity and to not further systemic injustices facing minority, BIPOC, and other non-majority communities. This can be accomplished via different methods, including ensuring that any involved recruitment sites service a diverse and representative client/patient base; partnering with local and regional memory consultation clinics that service large portions of the local/regional population; partnership with local and regional organizational chapters such as the Alzheimer's Association to ensure greater reach of recruitment strategies; and more. Additionally, future studies may wish to revisit inclusion/exclusion criteria used within this study, as the criteria used in this study may lead to over-exclusion of prospective participants. Specifically, the criteria of being a direct family member of the care-recipient may be dropped in

future studies to include non-family caregivers (e.g., friends, life partners not identified as legal family, etc.), as this could both increase overall recruitment as well as diversity and inclusivity of sampling methods.

A fourth limitation within this study may be the online setting in which the treatment protocol was delivered. As previously discussed, qualitative data gathered from the participants throughout the course of the intervention protocol demonstrated significant accessibility difficulties with online treatment modalities – especially for individuals who are asked to engage in group therapy about caregiver burden and distress while in the same home as their care-recipient (and as evidenced via qualitative observations and reports during the treatment protocol, often in the adjacent room). While the utilization of the online therapeutic modality was largely due to COVID-19 safety accommodations, it was also done in-part as an attempt to increase accessibility for dementia caregivers. The National Institute of Health and National Institute on Aging cites telehealth options as means to increase accessibility to care for individuals with dementia and their caregivers, as telehealth services reduce need to leave the home, travel-related strain, and time-related strain on caregivers (NIA, 2020). The Alzheimer's Association also recommends telehealth options for caregivers (Alzheimer's Association, 2020), and the American Medical Association has advocated for the permanent expansion of telehealth as a service option to increase accessibility to various populations and groups (AMA, 2021).

While the benefits of telehealth and telemental health services have become clear over the course of the COVID-19 pandemic, it is important to note that while these services may increase accessibility to some (even many) groups/populations, the blanket implementation of telehealth services may actually hinder access to services for other populations – one of those potential populations may include dementia caregivers. While this study is not advocating for the

removal of telehealth services for this population, the qualitative results collected from study participants do warrant further investigation into the feasibility of an online treatment protocol for caregiver burden. Specifically, it may be beneficial for future studies of online caregiver burden interventions to incorporate focus group methodologies to directly assess specific needs and potential barriers to access towards online versus in-person healthcare options for individuals within this specific community. Specifically, items that may be worth further exploration with focus groups include, but may not be limited to, preferences for intervention modality (including group vs. individual, in-person vs. telehealth, brief treatment vs. extended or longer-term treatment), specific barriers to accessing treatment, and the potential to include specific programs that incorporate the care-recipients to increase access to treatment.

Additionally, a fairly new phenomenon since the advent of widescale implementation of telehealth practices due to COVID-19 has been labeled “Zoom fatigue” (Fosslien & Duffy, 2020). While originally described within the corporate/business setting, Zoom fatigue encompasses the physical and mental exhaustion/fatigue from engaging via online meeting platforms such as Zoom, BlueJeans, Skype, and others. Prior to the COVID-19 pandemic, a vast majority of conference meetings (and therapy sessions) were held in-person, allowing for more natural modulation of eye contact, greater ease with being present in the physical space of the group, less extraneous distractions, and greater ability to maintain work-life (or therapy-life) boundaries (Fosslien & Duffy, 2020). While these items are absent (or more difficult to access) on tele-based platforms, individuals have also experienced increased demands for multi-tasking (given ease of access to various web- or computer-based applications), increased self-consciousness due to increased focus on one’s own self-presentation, increased feelings of overstimulation from constant screen-time, and overall increased cognitive load due to

hyperfocus requirements (Fosslien & Duffy, 2020). These findings have also been found to extend to telehealth and telepsychotherapy settings as well, both for the clients/patients and for the clinicians (Burgoyne & Cohn, 2020; Hickman, 2020; Kashyap et al., 2020; Lynch et al., 2021). As a result, it is possible that the phenomenon of Zoom fatigue, leading to potential disenfranchisement with tele-based healthcare modalities, may have been a possible contributing factor to lack of recruitment in this study. However, this conclusion is based on speculation at this time – in examining the literature, much of the research around telehealth appears to be on the efficacy and effectiveness in comparison to in-person therapy practices, with little research on client/patient preferences conducted to date. This is to be expected, as the field is still fairly early in the widescale and necessary implementation of telehealth practices due to the COVID-19 pandemic. As additional research on telehealth practices continues, it would likely be beneficial to also explore client/patient preferences and how the impact of Zoom fatigue may impact one's preference for in-person versus telehealth services.

A fifth potential limitation within this study is the use of a direct referral source recruitment strategy rather than an on-site recruitment procedure. While direct referral source recruitment has posed effective in meeting clinical research recruitment goals in prior studies, on-site recruitment strategies in which a research administrator is able to meet directly with a prospective participant at the time they either express interest or are first informed about the study do tend to yield greater recruitment results (Greenfield et al., 2014). Because of the COVID-19 pandemic and role constraints of the research administrators, an on-site recruitment strategy could not be implemented, making a direct referral source recruitment strategy the optimal option. Regardless, it is possible that an on-site recruitment procedure would have yielded greater recruitment results and therefore added to the overall feasibility of this study's



recruitment procedures. If on-site recruitment strategies are not accessible for research protocols, a virtual warm-handoff procedure may be a viable alternative. In the warm-handoff procedure (sometimes referred to as a “handshake” procedure), the trusted clinician (i.e., the referring clinician) meets with the research administrator alongside the prospective participant to allow for introductions and bridging of trust; a virtual warm-handoff would have this same procedure occur via virtual modalities (e.g., phone conference, teleconference, etc.; Kim et al., 2021). This type of procedure has been found to be particularly efficacious in studies meeting recruitment goals during the global COVID-19 pandemic when in-person recruitment may not be permitted for safety reasons (Kim et al., 2021). It is recommended that future studies examining the feasibility of this research and intervention protocol utilize either an on-site recruitment procedure or a virtual warm-handoff procedure if possible to optimize potential recruitment results.

A sixth potential limitation within this study is the lack of a control or comparison group. While it is common for feasibility studies to not include a control or comparison condition, as the primary purpose of these studies is to determine if a particular procedure/protocol can be implemented in larger-scale pilot/RCT studies (Arain et al., 2010), it is nonetheless a limitation in this study’s design. Without a control or comparison group, this study cannot control for regression to the mean within the outcome data, nor can it make any insinuations about causal statements regarding the group treatment protocol and group climate or the included outcome measures. Therefore, the internal validity of this study may be called into question. Again, though, it is important to note that the purpose of this study in assessing feasibility of the treatment protocol was not to determine causal relationships, but instead to determine whether this treatment protocol demonstrates enough promise to warrant further investigation into its use

for future pilot/RCT and efficacy studies. Future studies may seek to incorporate a control or waitlist group to further protect the internal validity of the study's design and further support feasibility of this treatment protocol. Additionally, a comparison/control group is strongly recommended after feasibility of this treatment protocol has been empirically established to assess for aspects of potential efficacy.

Another limitation of this study is the lack of follow-up assessments. Again, while the primary aim of this study was not to assess for objective symptom improvement or preliminary efficacy of the treatment protocol, the use of follow-up assessments at 3-months, 6-months, and/or 1-year post-treatment could have proved insightful in providing information pertaining to the potential feasibility of this treatment protocol in creating long-standing treatment gains. While future studies further examining the feasibility of this treatment protocol may not need follow-up assessments incorporated into their study design, future pilot/RCT studies (after feasibility has been empirically established) should consider follow-up assessment measures to assess for potential post-treatment durability and maintenance of therapeutic gains.

A further limitation of this study is that treatment fidelity to the manualized treatment protocol could not be assessed directly. Ideally, treatment sessions would be monitored by a separate party within the research team not directly involved in the administration of the intervention. Monitoring can occur via live observation, recording audio and/or video, and/or the use of standardized provider checklists to objectively assess fidelity to the protocol (Borrelli et al., 2005). While the treatment administrator took detailed notes of group sessions which were reviewed in individual supervision with a licensed provider who was familiar with the treatment manual, no formal monitoring was implemented to ensure treatment fidelity due to institutional review constraints. Future studies should incorporate treatment monitoring to ensure treatment

fidelity in accordance with the National Institute of Health (NIH) Behavioral Change Consortium (BCC) fidelity framework (Borelli et al., 2005).

Also positing a limitation in this study is the lack of data from recruitment sites about client/patient traffic through the respective clinics and information on how many participants were either referred or who viewed the referral information for this study. Due to institutional review constraints, information from the recruitment sites on how many clients/patients were seen at the clinic who may qualify for this study could not be collected. The combination of passive referral recruitment (i.e., flyers posted in client/patient waiting areas and clinical offices for prospective participants to self-refer) and active referral recruitment (i.e., providers at each site being instructed to provide flyers to clients along with information on the research study) poses an additional challenge in identifying how many prospective participants learned about the study and therefore could have contacted a researcher to express interest. Future studies of feasibility should attempt to utilize more standardized, systematic, and measurable methods of participant recruitment (Aitken et al., 2003). These methods may include, but are not limited to, focusing on active recruitment in which recruiters track the number of flyers provided to prospective participants, use of client databases for researchers to directly contact prospective participants with contact tracking, using a warm-handoff recruitment method that will allow clinicians and researchers to directly track how many people are informed of the study procedures (including tracking of how many participants are informed but decline to speak with a researcher for more information), and more. Additionally, researchers and participating clinicians should seek to include demographic information of all those informed of the study if possible, including age, race/ethnicity, gender, reason for declining participation, etc. to examine if recruitment strategies may be systematically skewed (Aitken et al., 2003).

Lastly, it needs to be noted that the primary research investigator of this study was also the one who led the therapy group, administered the treatment protocol, and collected survey data from participants. While survey data was collected in a manner that ensured participant anonymity, the multiple roles of the research administrator nonetheless poses a question for the presence of potential response biases among the participants. This may be especially relevant given the fact that the STTS-R asks multiple questions directly assessing participant satisfaction with the therapist. If participant responses to questionnaires are biased by a halo effects (i.e., the tendency to respond in an overtly positive manner; Whitcomb et al., 2014), these results may further be called into question. In future studies, the question of halo effect can be circumnavigated somewhat by ensuring that researchers do not overlap in research roles to reduce potential impacts of response biases. Because response biases are often a concern with many behavioral rating scales, future studies may also seek to incorporate measures that include validity scales which can directly assess the potential presence of response biases (Whitcomb et al., 2014).

## **Conclusions**

The present study is among the first to examine the feasibility of a theoretically informed, multi-component, online, synchronous, cognitive behavioral, group therapy intervention for the reduction of caregiver burden among primary family caregivers of persons with dementia. While this study certainly has its limitations, and the impact of the COVID-19 pandemic has been significant, the study nonetheless provides a wealth of data and information that can be used to further inform future feasibility studies. While many of the feasibility hypotheses in this study were not supported, some of the results did provide evidence in support of potential areas of

feasibility which can be expounded upon in future studies, such as the clinically significant changes noted in group cohesion and caregiver burden scores across treatment.

While the lack of ample participant recruitment renders the results of this study inconclusive, the research questions posed within this study need to be investigated further. Additionally, further research is needed on theoretically informed, multi-component, and accessible group-based treatments for primary family caregivers of persons with dementia. With trends of at-home caregiving for individuals diagnosed with dementia on the rise, and the potential adverse effects of caregiver burden across all spheres of an individual's life, it is imperative that research continues to inform ways in which clinicians and healthcare providers can help ease caregiver burden for so many around the world.

## REFERENCES

- Aboulafia-Brakha, T., Suchecki, D., Gouveia-Paulino, F., Nitrini, R., & Ptak, R. (2014). Cognitive-behavioural group therapy improves a psychophysiological marker of stress in caregivers of patients with Alzheimer's disease. *Aging & Mental Health, 18*, 801-808. doi: 10.1080/13607863.2014.880406.
- Acton, G. & Kang, J. (2001). Interventions to reduce the burden of caregiving for an adult with dementia: a meta-analysis. *Research in Nursing & Health, 24*, 349-360.
- Adelman, R., Timanova, L., Delgado, D., Dion, S., & Lachs, M. (2014). Caregiver burden: a clinical review. *Journal of the American Medical Association, 311*, 1052-1059.
- Ågren, S., Evangelista, L., & Strömberg, A. (2011). Do partners of patients with chronic heart failure experience caregiver burden? *European Journal of Cardiovascular Nursing, 9*, 254-262. doi: 10.1016/j.ejcnurse.2010.03.001.
- Aitken, L., Gallagher, R., & Madronio, C. (2003). Principles of recruitment and retention in clinical trials. *International Journal of Nursing Practice, 9*, 338-346.
- Albert, M. (1990). Caregiving as a cultural system: conceptions of filial obligation and parental dependency in urban America. *American Anthropologist, 82*, 319-331. doi: 10.1525/aa.1990.92.2.02a00040.
- Alexopolous, G., & Kelly, R. (2009). Research advances in geriatric depression. *World Psychiatry, 2009*, 140-149. doi:10.1002/j.2051-5545.2009.tb00234.x.
- Ali, S. & Bokharey, I. (2015). Efficacy of cognitive behavior therapy among caregivers of dementia: an outcome study. *Pakistan Journal of Psychological Research, 30*, 249-269.

- Altpeter, M., Gwyther, L., Kennedy, S., Patterson, T., & Derence, K. (2013). From evidence to practice: using the RE-AIM framework to adapt the REACH II caregiver intervention to the community. *Dementia*, 0(0). 1-10. doi: 10.1177/1471301213494499.
- Alzheimer's Association. (2016). 2016 Alzheimer's disease facts and figures. *Alzheimer's and Dementia*, 12(4). Retrieved from [http://www.alz.org/documents\\_custom/2016-facts-and-figures.pdf](http://www.alz.org/documents_custom/2016-facts-and-figures.pdf)
- Alzheimer's Association. (2018). 2018 Alzheimer's disease facts and figures. Retrieved from Alzheimer's Association:  
<https://www.alz.org/media/HomeOffice/Facts%20and%20Figures/facts-and-figures.pdf>
- Alzheimer's Association. (2019). *Caregiver stress*. Retrieved from <https://www.alz.org/help-support/caregiving/caregiver-health/caregiver-stress>.
- Alzheimer's Association. (2020). Promoting caregiving across the full community: the role for public health strategies. Retrieved from:  
<https://www.alz.org/media/Documents/alzheimers-dementia-promoting-caregiving-across-full-community.pdf>
- Alzheimer's Association. (2021). Alzheimer's disease facts and figures: special report – race, ethnicity, and Alzheimer's in America. *Alzheimer's & Dementia*, 17, 91-104.
- American Medical Association. (2020). *Telehealth Implementation Playbook*. Retrieved from <https://www.ama-assn.org/system/files/2020-04/ama-telehealth-playbook.pdf>.
- American Medical Association. (2021, November 22). *Telehealth should be lasting care mode, not a temporary measure*. Retrieved from: <https://www.ama-assn.org/practice-management/digital/telehealth-should-be-lasting-care-mode-not-temporary-measure>

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5<sup>th</sup> ed.). Arlington, VA: American Psychiatric Association.
- American Psychological Association. (2017). *Ethical principles of psychologists and code of conduct* (2002, amended effective June 1, 2010, and January 1, 2017). Retrieved from <https://www.apa.org/ethics/code/>.
- Anderson, P., Edwards, S., & Goodnight, J. (2016). Virtual reality and exposure group therapy for social anxiety disorder: results from a 4-6 year follow-up. *Cognitive Therapy & Research, 41*, 230-236. doi: 10.1007/s10608-016-9820-y.
- Aneshensel, C., Pearlin, L., & Schuler, R. (1993). Stress, role captivity, and the cessation of caregiving. *Journal of Health and Social Behavior, 34*, 54-70.
- Araim, M., Campbell, M., Cooper, C., & Lancaster, G. (2010). What is a pilot or feasibility study? A review of current practice and editorial policy. *BMC Medical Research Methodology, 10*(67), 1-7.
- Au, A., Gallagher-Thompson, D., Wong, M., Leung, J., Chan, W., Chan, C., Lu, H., Lai, M., & Chan, K. (2015). Behavioral activation for dementia caregivers: scheduling pleasant events and enhancing communications. *Clinical Interventions in Aging, 10*, 611-619. doi: 10.2147/CIA.S72348.
- Axelrod, R. (1973). Schema theory: an information processing model of perception and cognition. *The American Political Science Review, 67*, 1248-1266.
- Bartolo, M., Luca, D., Serrao, M., Sinforiani, E., Zucchella, C., & Sandrini, G. (2010). Caregiver burden and needs in community neurorehabilitation. *Journal of Rehabilitation Medicine, 42*, 818-822. doi: 10.2340/16501977-0612.
- Bandura, A. & Walters, R. (1977). *Social learning theory*. Englewood Cliffs, NJ: Prentice-Hall.



- Bauer, R., Bauer, M., Spiessl, H., & Kagerbauer, T. (2012). Cyber-support: an analysis of online self-help forums (online self-help forums in bipolar disorder). *Nordic Journal of Psychiatry*, 67, 185-190. doi: 10.3109/08039488.2012.700734.
- Beck, A. (1991). Cognitive therapy: a 30-year retrospective. *American Psychologist*, 46, 368-370.
- Beck, A. & Clark, D. (1997). An information processing model of anxiety: automatic and strategic processes. *Behavior Research in Therapy*, 35, 49-58.
- Beck, A., Epstein, N., Brown, G., & Steer, R. (1988). An inventory for measuring clinical anxiety: psychometric properties. *Journal of Consulting and Clinical Psychology*, 56, 893-897. doi:10.1037/0022-006X.56.6.893
- Beck, J. (2011). *Cognitive Behavior Therapy: Basics and Beyond, Second Edition*. New York, NY: The Guilford Press.
- Beck Institute. (n.d.). *History of cognitive behavior therapy*. Retrieved from <https://beckinstitute.org/about-beck/team/our-history/history-of-cognitive-therapy/>
- Beckner, V., Howard, I., Vella, L., & Mohr, D. (2010). Telephone-administered psychotherapy for depression in MS patients: moderating role of social support. *Journal of Behavioral Medicine*, 33, 47-59.
- Beentjes, T., Goosens, P., & Poslowsky, I. (2012). Caregiver burden in bipolar hypomania and mania: a systematic review. *Perspectives in Psychiatric Care*, 48, 187-197.
- Belle, S., Burgio, L., Burns, R., Coon, D., Czaja, S., Gallagher-Thompson, D., Gitlin, L., Klinger, J., Koepke, K., Lee, C., Martindale-Adams, J., Nichols, L., Schulz, R., Stahl, S., Stevens, A., Winter, L., & Zhang, S. (2006). Enhancing the quality of life of dementia

- caregivers from different ethnic or racial groups: a randomized, controlled trial. *Annals of Internal Medicine*, 145, 727-738.
- Berger, T. (2017). The therapeutic alliance in internet interventions: a narrative review and suggestions for future research. *Psychotherapy Research*, 27, 511-524. doi: 10.1080/10503307.2015.119908.
- Bjelland, I., Dahl, A., Haug, T., & Neckelmann, D. (2001). The validity of the Hospital Anxiety and Depression Scale: an updated literature review. *Journal of Psychosomatic Research*, 52, 69-77.
- Black, B., Johnston, D., Rabins, P., Morrison, A., Lyketsos, C., & Samus, Q. (2013). Unmet needs of community-residing persons with dementia and their informal caregivers: findings from the maximizing independence at home study. *Journal of the American Geriatrics Society*, 61, 2087-2095. doi: 10.1111/jgs.12549.
- Black, W. & Almeida, O. (2004). A systematic review of the association between the behavioral and psychological symptoms of dementia and burden of care. *International Psychogeriatrics*, 16, 295-315.
- Borelli, B., Sepinwall, D., Ernst, D., Bellg, A., Czajkowski, S., Breger, R., DeFrancesco, C., Levesque, C., Sharp, D., Ogedegbe, G., Resnick, B., & Orwig, D. (2005). A new tool to assess treatment fidelity and evaluation of treatment fidelity across 10 years of health behavior research. *Journal of Consulting and Clinical Psychology*, 73, 852-860. doi: 10.1037/0022-006X.73.5.852.
- Bossio, J., Basson, R., Driscoll, M., Correia, S., & Brotto, L. (2018). Mindfulness-based group therapy for men with situational erectile dysfunction: a mixed-methods feasibility

- analysis and pilot study. *Journal of Sexual Medicine*, 15, 1478-1490. doi: 10.1016/j.jsxm.2018.08.013.
- Bourgeois, M., Schulz, R., Burgio, L., & Beach, S. (2002). Skills training for spouses of patients with Alzheimer's disease: outcomes of an intervention study. *Journal of Clinical Geropsychology*, 8, 53-73.
- Brodaty, H., Thompson, C., Thompson, C., & Fine, M. (2005). Why caregivers of people with dementia and memory loss don't use services. *International Journal of Geriatric Psychiatry*, 20, 1-10. doi: 10.1002/gps.1322.
- Brodaty, H., Woodward, M., Boundy, K., Ames, D., & Balshaw, R. (2014). Prevalence and predictors of burden in caregivers of people with dementia. *The American Journal of Geriatric Psychiatry*, 22, 756-765. doi: 10.1016/j.jagp.2013.05.004.
- Brown, J., Sellwood, K., Beecham, J., Slade, M., Andiappan, M., Landau, S., Johnson, T., & Smith, R. (2011). Outcome, costs, and patient engagement for group and individual CBT for depression: a naturalistic clinical study. *Behavioural and Cognitive Psychotherapy*, 39, 355-358. Doii: 10.1017/S135246581000072X.
- Bruin, E., Bögels, S., Oort, F., & Meijer, A. (2015). Efficacy of cognitive behavioral therapy for Insomnia in adolescents: a randomized controlled trial with internet therapy, group therapy, and a waiting list condition. *Sleep*, 38, 1913-1926. doi: 10.5665/sleep.5240.
- Bujang, M., Omar, E., & Baharum, N. (2018). A review on sample size determination for Cronbach's alpha test: a simple guide for researchers. *Malaysian Journal of Medical Sciences*, 25, 85-99. doi: 10.21315/mjms2018.25.6.9.
- Burgio, L., Collins, I., Schmid, B., Wharton, T., McCallum, D., & DeCoster, J. (2009). Translating the REACH caregiver intervention for use by area agency on aging

- personnel: the REACH OUT program. *The Gerontologist*, 49, 103-116. Doi: 10.1093/geront/gnp.012.
- Burgoyne, N. & Cohn, A. (2020). Lessons from the transition to relational teletherapy during COVID-19. *Family Process*, 59, 974-988. doi: 10.1111/famp.12589.
- Burrow-Sanchez, J. & Wrona, M. (2012). Comparing culturally accommodated versus standard group CBT for Latino adolescents with substance use disorders: a pilot study. *Cultural Diversity & Ethnic Minority Psychology*, 18, 373-383. doi: 10.1037/a0029439.
- Camargos, E., Souza, A., Nascimento, A., Morais-e-Silva, A., Quintas, J., Louzada, L., & Medeiros-Souza, P. (2012). Use of psychotropic medications by caregivers of elderly patients with dementia: is this a sign of caregiver burden? *Arq. Neuro-Psiquiatr.*, 70, 169-174. doi: 10.1590/S00004-282X2012000300003.
- Campbell, B., Manuel, J., Manser, S., Peavy, K., Stelmokas, J., McCarty, D., & Guydish, J. (2013). Assessing fidelity of treatment delivery in group and individual 12-step facilitation. *Journal of Substance Abuse Treatment*, 44, 169-176. doi: 10.1016/j.jsat.2012.07.003.
- Carron, A. & Brawley, L. (2000). Cohesion: conceptual and measurement issues. *Small Group Research*, 31, 89-106.
- Caserta, M., Lund, D., & Wright, S. (1996). Exploring the caregiver burden inventory (CBI): further evidence for a multidimensional view of burden. *International Journal of Aging and Human Development*, 43, 21-34.
- Cassie, K. & Sanders, S. (2008). Familial caregivers of older adults. *Journal of Gerontological Social Work*, 1, 293-320.

Centers for Disease Control and Prevention (30 October 2019). Caregiving for a person with Alzheimer's disease or a related dementia. Retrieved from:

<https://www.cdc.gov/aging/caregiving/alzheimer.htm>

Chen, E. & Mallinckrodt, B. (2002). Attachment, group attraction, and self-other agreement in interpersonal circumplex problems and perceptions of group members. *Group Dynamics: Theory, Research, & Practice*, 6, 311-324. doi: 10.1037//1089-2699.6.4.311.

Chester, A. & Glass, C. (2006). Online counselling: a descriptive analysis of therapy services on the Internet. *British Journal of Guidance & Counseling*, 34, 145-160. doi: 10.1080/03069880600583170.

Chien, L., Chu, H., Guo, J., Liao, Y., Chang, L., Chen, C., & Chou, K. (2011). Caregiver support groups in patients with dementia: a meta-analysis. In *Database of Abstracts of Reviews of Effects (DARE): Quality-Assessed Reviews*. York, UK: Centre for Reviews and Dissemination.

Choi, I., Zou, J., Titov, N., Dear, B., Li, S., Johnston, L., Andrews, G., & Hunt, C. (2012). Culturally attuned internet treatment for depression amongst Chinese Australians: a randomized controlled trial. *Journal of Affective Disorders*, 136, 459-468. doi: 10.1016/j.jad.2011.11.003.

Chou, K., LaMontagne, L., & Hepworth, J. (1999). Burden experienced by caregivers of relatives with dementia in Taiwan. *Nursing Research*, 48, 206-214.

Chu, H., Yang, C., Liao, Y., Chang, L., Chen, C., Chieh, C., & Chou, K. (2011). The effects of a support group on dementia caregivers' burden and depression. *Journal of Aging and Health*, 23, 228-241. doi: 10.1177/0898264310381522.

- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences, second edition*. Hillsdale, NJ: Lawrence Erlbaum Associates.
- Colón, Y. & Stern, S. (2011). Counseling groups online: theory and framework. In G. Stricker & C. Speyer (Eds.), *Online Counseling: a Handbook for Mental Health Professionals* (pp. 183-202). Academic Press.
- Conroy, R. (2015). Sample size: a rough guide. Retrieved from:  
<http://www.beaumontethics.ie/docs/application/samplesizecalculation.pdf>.
- Cooch, J. & Doyle, C. (2002). Working alliance in online therapy as compared to face-to-face therapy: preliminary results. *CyberPsychology & Behavior*, 5, 95-105. doi: 10.1089/109493102753770480.
- Cook, J. & Doyle, C. (2002). Working alliance in online therapy as compared to face-to-face therapy: preliminary results. *CyberPsychology & Behavior*, 5, 95-105.
- Coon, D. & Evans, B. (2009). Empirically based treatments for family caregiver distress: what works and where do we go from here? *Geriatric Nursing*, 30, 426-436.
- Cooper, C., Katona, C., Orrell, M., & Livingston, G. (2008). Coping strategies, anxiety, and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 23, 929-936. doi: 10.1002/gps.2007.
- Craigie, M. & Nathan, P. (2009). A nonrandomized effectiveness comparison of broad-spectrum group CBT to individual CT for depressed outpatients in a community mental health setting. *Behavior Therapy*, 40, 302-314.
- Crowe, T. & Grenyer, B. (2008). Is therapist alliance or whole group cohesion more influential in group psychotherapy outcomes? *Clinical Psychology & Psychotherapy*, 15, 239-346. doi: 10.1002/cpp.583.

- Cully, J. & Teten, A. (2008). *A therapist's guide to brief cognitive behavioral therapy*. Houston, TX: Department of Veteran's Affairs South Central Mental Illness Research, Education, and Clinical Center (MIRECC).
- Curtin, K. & Eacho, C. (2012). Dimensions of social climate as predictors of satisfaction with multifamily therapy groups for families of students with emotional and behavioral disorders. *Group, 36*, 283-301.
- Cutrona, C. & Russell, D. (1987). The provisions of social relationships and adaptation to stress. *Advances in Personal Relationships, 1*, 37-67.
- Dadds, M. & McHugh, T. (1992). Social support and treatment outcome in behavioral family therapy for child conduct problems. *Journal of Consulting and Clinical Psychology, 60*, 252-259.
- Daft, R. & Lengel, R. (1986). Organizational information requirements, media richness and structural designs. *Management Science, 32*, 554-571.
- Davis, L., Burgio, L., Buckwalter, K., & Weaver, M. (2004). A comparison of in-home and telephone-based skill training interventions with caregivers of persons with dementia. *Journal of Mental Health & Aging, 10*, 31-44.
- Dementia Care Central. (2018, September 24). *Respite care for dementia caregivers*. Retrieved from <https://www.dementiacarecentral.com/caregiverinfo/careoptions/respite/>
- Diehl, J., Mayer, T., Förstl, H., & Kurz, A. (2003). A support group for caregivers of patients with frontotemporal dementia. *Dementia, 2*, 151-161.
- Dimidjian, S., Barrera, M., Martell, C., Muñoz, R., & Lewinsohn, P. (2011). The origins and current status of behavioral activation treatment for depression. *Annual Review of Clinical Psychology, 7*, 1-38.

- Dissanayaka, N., Pye, D., Mitchell, L., Byrne, G., O'Sullivan, J., Marsh, R., & Pachana, N. (2017). Cognitive behavior therapy for anxiety in Parkinson's disease: outcomes for patients and caregivers. *Clinical Gerontologist*, 40, 159-171. doi: 10.1080/07317115.2016.1240131.
- Dixon, L. & Linardon, J. (2019). A systematic review and meta-analysis of dropout rates from dialectical behaviour therapy in randomized controlled trials. *Cognitive Behaviour Therapy*, doi: 10.1080/16506073.2019.1620324.
- D'Onofrio, G., Sancarlo, D., Addante, F., Ciccone, F., Cascavilla, L., Paris, F., Picoco, M., Nuzzaci, C., Elia, A., Greco, A., Chiarini, R., Panza, F., & Pilotto, A. (2014). Caregiver burden characterized in patients with Alzheimer's disease or vascular dementia. *International Journal of Geriatric Psychiatry*, 30, 891-899. doi: 10.1002/gps.4232
- Drossel, C., Fisher, J., & Mercer, V. (2011). A DBT skills training group for family caregivers of persons with dementia. *Behavior Therapy*, 42, 109-119.
- Eaton, A., Walmsley, S., Craig, S., Rourke, S., Sota, T., McCullagh, J., & Fallon, B. (2019). Protocol for a pilot randomized controlled trial evaluating feasibility and acceptability of cognitive remediation group therapy compared with mutual aid group therapy for people ageing with HIG-associated neurocognitive disorder (HAND) in Toronto, Canada. *BMJ Open*, 9, 1-8. doi: 10.1136/bmjopen-2019-033183.
- Egan, K., Pinto, A., Bighelli, I., Berg-Weger, M., Straten, A., Albanese, E., & Pot, A. (2018). Online training and support programs designed to improve mental health and reduce burden among caregivers of people with dementia: a systematic review. *Journal of the American Medical Directors Association*, 19, 200-206.



- Eldridge, S., Lancaster, G., Campbell, M., Thabane, L., Hopewell, S., Coleman, C., & Bond, C. (2016). Defining feasibility and pilot studies in preparation for randomized controlled trials: development of a conceptual framework. *PLoS ONE*, *11*(3), 1-22. doi: 10.1371/journal.pone.0150205.
- Ellis, C., Peterson, M., Bufford, R., & Benson, J. (2014). The importance of group cohesion in inpatient treatment of combat-related PTSD. *International Journal of Group Psychotherapy*, *64*, 209-226.
- Ellis, L., Campbell, A., Sethi, S., & O'Dea, B. (2011). Comparative randomized trial of an online cognitive-behavioral therapy program and an online support group for depression and anxiety. *Journal of CyberTherapy & Rehabilitation*, *4*, 461-167.
- Evans, M., Donelle, L., & Hume-Loveland, L. (2012). Social support and online postpartum depression discussion groups: a content analysis. *Patient Education & Counseling*, *87*, 405-410. doi: 10.1016/j.pec.2011.09.011.
- Evans, N. & Jarvis, P. (1986). The Group Attitude Scale: a measure of attraction to group. *Small Group Behavior*, *17*, 203-216.
- Ferrara, M., Langiano, E., Brango, T., Cioccio, L., Bauco, C., & De Vito, E. (2008). Prevalence of stress, anxiety, and depression in Alzheimer caregivers. *Health and Quality of Life Outcomes*, *6*(93), 1-5. doi: 10.1186/1477-7525-6-93.
- Fosslien, L. & Duffy, M. (2020, August 29). How to combat Zoom fatigue. *Harvard Business Review*. Retrieved from <https://hbr.org/2020/04/how-to-combat-zoom-fatigue>.
- Freeland, K. (2016, March 30). *Feasibility and pilot studies* [PPT]. Seminar on the Nuts and Bolts of Behavioral Intervention Development, presented at the 37<sup>th</sup> Annual Meeting and Scientific Sessions of the Society of Behavioral Medicine, Washington: DC.

- Gainsbury, S. & Blaszczynski, A. (2011). A systematic review of internet-based therapy for the treatment of addictions. *Clinical Psychology Review*, 31, 490-498. doi: 10.1016/j.cpr.2010.11.007.
- Gaugler, J., Kane, R., & Newcomer, R. (2007). Resilience and transitions from dementia caregiving. *Journal of Gerontology*, 62B, 38-44. doi: 10.1093/geronb/62.1.P38.
- Gaguler, J., Roth, D., Haley, W., & Mittelman, M. (2008). Can counseling and support reduce Alzheimer's caregivers' burden and depressive symptoms during the transition to institutionalization? Results from the NYU caregiver intervention study. *Journal of the American Geriatric Society*, 56, 421-428. doi: 10.1111/j.1532-5415.2007.01593.x.
- Gertner, E. (2020). COVID-19 trial co-enrolment and subsequent enrolment. *The Lancet Correspondence*, 396, 461-462. doi: 10.1016/S0140-6736(20)35137-3.
- Gitlin, L., Burzio, L., Mahoney, D., Burns, R., Zhang, S., Schulz, R., Belle, S., Czaja, S., Gallagher-Thompson, D., Huack, W., & Ory, M. (2003). Effect of multicomponent interventions on caregiver burden and depression: the REACH multisite initiative at 6-month follow-up. *Psychological Aging*, 18, 361-374. doi: 10.1037/0882-7974.18.3.361.
- Givens, J., Mezzacappa, C., Heeren, T., Yaffe, K., & Fredman, L. (2013). Depressive symptoms among dementia caregivers: the role of mediating factors. *American Journal of Geriatric Psychiatry*, 22, 481-488. doi: 10.1016/j.agp.2012.08.010
- Glueckauf, R., Ketterson, T., Loomis, J., & Dages, P. (2004). Online support and education for dementia caregivers: overview, utilization, and initial program evaluation. *Telemedicine Journal and E-Health*, 10, 223-232.
- Gottlieb, B. & Bergen, B. (2010). Social support concepts and measures. *Journal of Psychosomatic Research*, 69, 511-520. doi: 10.1016/j.jpsychores.2009.10.001.

- Graffam, S. & Johnson, A. (1987). A comparison of two relaxation strategies for the relief of pain and its distress. *Journal of Pain & Symptom Management*, 2, 229-231. doi: 10.1016/S0885-3924(87)80061-1.
- Greco, A., Pancani, L., Sala, M., Annoni, A., Steca, P., Paturzo, M., D'Agostino, F., Alvaro, R., & Vallone, E. (2017). Psychometric characteristics of the caregiver burden inventory in caregivers of adults with heart failure. *European Journal of Cardiovascular Nursing*, 16, 502-510. doi: 10.1177/1474515117693890.
- Greenberger, H. & Litwin, H. (2003). Can burdened caregivers be effective facilitators of elder care-recipient health-care? *Issues and Innovations in Nursing Practice*, 41, 332-341.
- Greenfield, S., Crisafulli, M., Kaufman, J., Freid, C., Bailey, G., Connery, H., Rapoza, M., & Rodolico, J. (2014). Implementing substance abuse group therapy clinical trials in real-world settings: challenges and strategies for participant recruitment and therapist training in the women's recovery group study. *American Journal on Addictions*, 23, 197-204. doi: 10.1111/j.1521.0391.2014.12099.x.
- Gwinnell, E. (2003). Unique aspects of internet relationships. In P. Wootton, P. Yellowlees, & P. McLaren (Eds.), *Telepsychiatry and E-Mental Health*. United Kingdom: LibraPharm.
- Hagemann, L., Luci, K., Sapra, M., Savla, J., Jacobs, L., & Yates, T. (2019). PAACC: a mindfulness-based multicomponent program for family caregivers of persons with dementia. *Innovation in Aging*, 3, S287-S288.
- Haines, K., Denehy, L., Skinner, E., Warrillow, S., & Berney, S. (2015). Psychosocial outcomes in informal caregivers of the critically ill: a systematic review. *Critical Care Medicine*, 43, 1112-1120. doi: 10.1097/CCM.0000000000000865.

- Handley, A., Egan, S., Kane, R., & Rees, C. (2015). A randomized controlled trial of group cognitive behavioural therapy for perfectionism. *Behaviour Research & Therapy*, 68, 37-47. doi: 10.1016/j.brat.2015.02.006.
- Hans, E. & Hiller, W. (2013a). A meta-analysis of nonrandomized effectiveness studies on outpatient cognitive behavioral therapy for adult anxiety disorders. *Clinical Psychology Review*, 33, 954-964. doi: 10.1016/j.cpr.2013.07.003.
- Hans, E. & Hiller, W. (2013b). Effectiveness of and dropout from outpatient cognitive behavioral therapy for adult unipolar depression: a meta-analysis of nonrandomized effectiveness studies. *Journal of Consulting & Clinical Psychology*, 81, 75-88. doi: 10.1037/a0031080.
- Harris, B. & Birnbaum, R. (2015). Ethical and legal implications on the use of technology in counselling. *Journal of Clinical Social Work*, 43, 133-141.
- Hayward, C., Varady, S., Albano, A., Thienemann, M., Henderson, L., & Schatzberg, A. (2000). Cognitive-behavioral group therapy for social phobia in female adolescents: results of a pilot study. *Journal of the American Academy of Child & Adolescent Psychiatry*, 39, 721-726. doi: 10.1097/00004583-200006000-00010.
- Hepburn, K., Lewis, M., Narayan, S., Center, B., Tornatore, J., Bremer, K., & Kirk, L. (2005). Partners in caregiving: a psychoeducation program affecting dementia family caregivers' distress and caregiving outlook. *Clinical Gerontologist*, 29, 53-69. doi: 10.1300/J018v29n01\_05.
- Hickman, S. (2020, April 6). Zoom exhaustion is real – here are six ways to find balance and stay connected. *University of Maryland Baltimore Digital Archive*. Retrieved from: <https://archive.hshsl.umaryland.edu/handle/10713/13776>.

- Higginson, I., Gao, W., Jackson, D., Murray, J., & Harding, R. (2010). Short-form Zarit Caregiver Burden Interviews were valid in advanced conditions. *Journal of Clinical Epidemiology*, 63, 535-542. doi: 10.1016/j.jclinepi.2006.06.014.
- Hogan, D., Jetté, N., Fiest, K., Roberts, J., Pearson, D., Smith, E., Roach, P., Kirk, A., Pringsheim, T., & Maxwell, C. (2016). The prevalence and incidence of frontotemporal dementia: a systematic review. *Canadian Journal of Neurological Sciences*, 43, 96-109. doi: 10.1017/cjn.2016.25.
- Høgland, P. & Hagtvet, K. (2019). Change mechanisms in psychotherapy: both improved insight and improved affective awareness are necessary. *Journal of Consulting and Clinical Psychology*, 87, 332-344. doi: 10.1037/ccp0000381.
- Holley, C. & Mast, B. (2009). The impact of anticipatory grief on caregiver burden in dementia caregivers. *The Gerontologist*, 49, 388-396. doi: 10.1093/geront/gnp061.
- Hurd, M., Martorell, P., Delavande, A., Mullen, K., & Langa, K. (2013). Monetary costs of dementia in the United States. *The New England Journal of Medicine*, 638, 1326-1334. doi: 10.1056/NEJMs1204629.
- Imel, Z., Laska, K., Jakupcak, M., & Simpson, T. (2013). Meta-analysis of dropout in treatments for post-traumatic stress disorder. *Journal of Consulting & Clinical Psychology*, 81, 394-404. doi: 10.1037/a0031474.
- Jellinger, K. (2010). Prevalence of dementia disorders in the oldest-old: an autopsy study. *Acta Neuropathologica*, 119, 421-233.
- Johnson, J., Burlingame, G., Olsen, J., Davies, R., & Gleave, R. (2005). Group climate, cohesion, alliance, and empathy in group psychotherapy: multilevel structural equation

- models. *Journal of Counseling Psychology*, 52, 310-321. doi: 10.1037/00022-0167.52.3.310.
- Johnston, M., Pollard, B., & Hennessey, P. (2000). Construct validation of the hospital anxiety and depression scale with clinical populations. *Journal of Psychosomatic Research*, 48, 579-584. doi: 10.1016/S0022-3999(00)00102-1.
- Kacovski, N., Fleming, J., Hawley, L., Huta, V., & Antony, M. (2013). Mindfulness and acceptance-based group therapy versus traditional cognitive behavioral group therapy for social anxiety disorder: a randomized controlled trial. *Behaviour Research & Therapy*, 51, 889-898. doi: 10.1016/j.brat.2013.10.007.
- Kalodner, C. (2011). Cognitive-behavioral theories. In D. Capuzzi & D. Gross (Eds.), *Counseling and psychotherapy, fifth edition* (pp. 193-213). Alexandria, VA: American Counseling Association.
- Kane, J., Surendranathan, A., Bentley, A., Barker, S., Taylor, J., Thomas, A., Allan, L., McNally, R., James, P., McKeith, I., Burn, D., & O'Brien, J. (2018). Clinical prevalence of Lewy body dementia. *Alzheimer's Research and Therapy*, 10, 1-8. doi: 10.1186/s13195-018-0350-6.
- Kayshap, H., Chandur, J., & Reddy, R. (2020). The loss of the shared space: process issues in telepsychotherapy. *Indian Journal of Psychological Medicine*, 5, 469-472. doi: 10.1177/0253717620952313.
- Kelly, B. & Petersen, R. (2007). Alzheimer's disease and mild cognitive impairment. *Neurologic Clinics*, 25, 577-609.

- Khatri, N., Marziali, E., Tchernikov, I., & Shepherd, N. (2014). Comparing telehealth-based and clinic-based group cognitive behavioral therapy for adults with depression and anxiety: a pilot study. *Clinical Interventions in Aging*, 9, 765-770. doi: 10.2147/CIA.S57832.
- Kim, N., Wilson, N., Mashburn, T., Reist, L., Westrick, S., Look, K., Kennelty, K., & Carpenter, D. (2021). Lessons learned recruiting a diverse sample of rural study participants during the COVID-19 pandemic. *International Journal of Drug Policy*, 97, 103344. doi: 10.1016/j.drugpo.2021.103344.
- Kingsep, P., Nathan, P., & Castle, D. (2003). Cognitive behavioural group treatment for social anxiety in schizophrenia. *Schizophrenia Research*, 63, 121-129. doi: 10.1016/S0920-9964(02)00376-6.
- Klarić, M., Frančišković, T., Pernar, M., Nemčić, I., Milićević, R., Černi, E., & Salčin, A. (2010). Caregiver burden and burnout in partners of war veterans with post-traumatic stress disorder. *Collegium Antropologicum*, 34, 15-21. 327-348.
- Kock, N. (2004). The psychobiological model: towards a new theory of computer-mediated communication based on Darwinian evolution. *Organization Science*, 15,
- Kraemer, K., Luberto, C., O'Bryan, E., Myssinger, E., & Cotton, S. (2016). Mind-body skills training to improve distress tolerance in medical students: a pilot study. *Teaching & Learning in Medicine*, 28, 219-228.
- Kwok, T., Au, A., Wong, B., Ip, I., Mak, V., & Ho, F. (2014). Effectiveness of online cognitive behavior therapy on family caregivers of people with dementia. *Clinical Interventions in Aging*, 9, 631-636. doi: 10.2147/CIA.S56337.

- Kwon, O., Ahn, H., Kim, H., & Park, K. (2017). Effectiveness of cognitive behavioral therapy for caregivers of people with dementia: a systematic review and meta-analysis. *Journal of Clinical Neurology*, 13, 394-404. doi: 10.3988/jcn.2017.13.4.394.
- Lai, D. (2010). Filial piety, caregiving appraisal, and caregiving burden. *Research on Aging*, 32, 200-223.
- Lancaster, G., Dodd, S., & Williamson, P. (2004). Design and analysis of pilot studies: recommendations for good practice. *Journal of Evaluation in Clinical Practice*, 10, 307-312. doi: 10.1111/j..2002.384.doc.x.
- Lawrence, R., Tennstedt, S., & Assmann, S. (1998). Quality of the caregiver-care recipient relationship: does it offset negative consequences of caregiving for family caregivers? *Psychology and Aging*, 13, 150-158. doi: 10.1037/0882-7974.13.1.150.
- Lederman, R., Gleeson, J., Wadley, G., D'Alfonso, S., Rice, S., Santesteban-Echarri, O., & Alvarez-Jimenez, M. (2019). Support for carers of young people with mental illness: design and trial of a technology-mediated therapy. *ACM Transactions on Computer-Human Interaction*, 26(4), 1-33.
- Lee, E. (2015). Do technology-based support groups reduce care burden among dementia caregivers? A review. *Journal of Evidence-Informed Social Work*, 15, 474-487. doi: 10.1080/15433714.2014.930362.
- Lee, Y. & Sung, K. (1988). Cultural influences on caregiving burden: cases of Koreans and Americans. *The International Journal of Aging and Human Development*, 46, 125-141. doi: 10.2190/PM2C-V93R-NE8H-JWGV.
- Lese, K. & MacNair-Semands, R. (2000). The Therapeutic Factors Inventory: development of a scale. *Group*, 24, 303-317.



- Lewandowski, J., Rosenberg, B., Parks, M., & Siegel, J. (2011). The effect of informal social support: face-to-face versus computer-mediated communication. *Computers in Human Behavior*, 27, 1806-1814. doi: 10.1016/j.chb.2011.03.008.
- Lewinsohn, P., Hoberman, H., Teri, L., & Hautzinger, M. (1985). An integrated theory of depression. (pp. 351-385). In Reizz, S. & Bootzin, R. (Eds.). *Theoretical issues in behavior therapy*. New York, NY: Academic Press.
- Limpawattana, P., Chindaprasirt, J., & Pimporm, J. (2012). Caregivers burden of older adults with chronic illnesses in the community: a cross-sectional study. *Journal of Community Health*, 38, 40-45.
- Lin, T., Yu, P., Lin, L., Liu, P., Li, Y., Hsu, C., Cheng, Y., Yeh, C., Wong, S., Pai, S., & Weng, C. (2018). A pilot-study to assess the feasibility and acceptability of an internet-based cognitive-behavior group therapy using video conference for patients with coronary artery heart disease. *PLoS One*, 13, 1-13. doi: 10.1371/journal.pone.0207931.
- Lingler, J., Schmidt, K., Gentry, A., Hu, L., & Terhorst, L. (2014). Perceived research burden assessment (PeRBA): instrument development and psychometric evaluation. *Journal of Empirical Research on Human Research Ethics*, 9, 46-49. doi: 10.1177/1556264614545037.
- Liu, Z., Chen, Q., & Sun, Y. (2017). Mindfulness training for psychological stress in family caregivers of persons with dementia: a systematic review and meta-analysis of randomized controlled trials. *Clinical Interventions in Aging*, 12, 1521-1529. doi: 10.2147/CIA.S146213.
- Lopez-Hartmann, M., Wens, J., Verhoeven, V., & Remmen, R. (2012). The effect of caregiver support interventions for informal caregivers of community-dwelling frail elderly: a

- systematic review. *International Journal of Integrated Care*, 12, 1-16. doi: 10.5334/ijic.845.
- Lovato, L., Hill, K., Hertert, S., Hunninghake, D., & Probstfield, J. (1997). Recruitment for controlled clinical trials: literature summary and annotated bibliography. *Controlled Clinical Trials*, 18, 328-357.
- Lynch, D., Stefancic, A., Cabassa, L., & Medalia, A. (2021). Client, clinician, and administrator factors associated with the successful acceptance of a telehealth comprehensive recovery service: a mixed methods study. *Psychiatry Resesarch*, 300, 1-8. doi: 10.1016/j.psychres.2021.11.113871.
- Machado, D., Laskoski, P., Severo, C., Bassols, A., Sfoggia, A., Kowacs, C., Krieger, D., Torres, M., Gastaud, M., Wellausen, R., Teche, S., & Eizirik, C. (2016). A psychodynamic perspective on a systematic review of online psychotherapy for adults. *British Journal of Psychotherapy*, 32, 79-108. doi: 10.1111/bjp.12204.
- Magan, A., Plastow, R., & Haddad, F. (2020). Impact of COVID-19 on research. *Bone & Joint Research*, 9, 531-533. doi: 10.1302/2046-3758.98.BJR-2020-0344
- Mallinckrodt, B. (1989). Social support and the effectiveness of group therapy. *Journal of Counseling Psychology*, 36, 170-175.
- Mamani, A., Weintraub, M., Maura, J., Andino, A., & Brown, C. (2018). The interplay among mindfulness, caregiver burden, and mental health in family members of individuals with dementia. *Professional Psychology: Research & Practice*, 49, 116-123. doi: 10.1037/pro000181.

- Mann, B., Gosens, T., & Lyman, S. (2012). Quantifying clinically significant change: a brief review of methods and presentation of a hybrid approach. *American Journal of Sports Medicine*, 40, 2385-2393. doi: 10.1177/0363546512457346.
- Marvardi, M., Mattioli, P., Spazzafumo, L., Mastroforti, R., Rinaldi, P., Polidori, M., Cherubini, A., Quartesan, R., Bartorelli, L., Bonaiuto, S., Cucinotta, D., Di Lorio, A., Gallucci, M., Giordano, M., Martorelli, M., Masaraki, G., Nieddu, A., Pettenati, C., Putzu, P., Solfrizzi, V., Tamaro, A., Tomassini, P., Vergani, C., Senin, U., & Mecocci, P.. (2005). The caregiver burden inventory in evaluating the burden of caregivers of elderly demented patients: results from a multicenter study. *Aging Clinical and Experimental Research*, 17, 46-53.
- Marziali, E. & Garcia, L. (2011). Dementia caregivers' responses to 2 internet-based intervention programs. *American Journal of Alzheimer's Disease & Other Dementias*, 26, 36-43. doi: 10.1177/1533317510387586.
- Marziali, E., Monroe-Blum, H., & McCleary, L. (1997). The contribution of group cohesion and group alliance to the outcome of group psychotherapy. *International Journal of Group Psychotherapy*, 47, 475-497. doi: 10.1080/00207284.1997.11490846.
- Marziliano, A., Applebaum, A., Moyer, A., Pessin, H., Rosenfeld, B., & Breitbart, W. (2021). The impact of matching to psychotherapy preferences on engagement in a randomized controlled trial for patients with advanced cancer. *Frontiers in Psychology*, 24, 426.
- Mason, A., Weatherly, H., Spilsbury, K., Arksey, H., Golder, S., Adamson, J., Drummond, M., & Glendinning, C. (2007). A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers. *Health Technology Assessment*, 11, np.

- Mather, M. & Scommegna, P. (2020, May 28). The demography of dementia and dementia caregiving. *Population Reference Bureau*. Retrieved from:  
<https://www.prb.org/resources/the-demography-of-dementia-and-dementia-caregiving/>
- Maxwell, S. & Delaney, H. (2004). *Designing Experiments and Analyzing Data: a Model Comparison Perspective, Second Edition*. Taylor & Francis Group, LLC: New York, NY.
- May, A., Diuvenvoorden, H., Korstjens, I., Weert, E., Hoekstra-Weebers, J., Borne, B., Mesters, I., Schans, C., & Ros, W. (2008). The effect of group cohesion on rehabilitation outcome in cancer survivors. *Psycho-Oncology*, 17, 917-925. doi: 10.1002/pon.1308.
- McDermut, W., Miller, I., & Brown, R. (2001). The efficacy of group psychotherapy for depression: a meta-analysis and review of the empirical research. *Clinical Psychology: Science and Practice*, 8, 98-116.
- McGill, B., Sansom-Daly, U., Wakefield, C., Ellis, S., Robertson, E., & Cohn, R. (2017). Therapeutic alliance and group cohesion in an online support program for adolescent and young adult cancer survivors: lessons from “recapture life.” *Journal of Adolescent and Young Adult Oncology*, 6, 568-572. doi: 10.1089/jayao.2017.0001.
- Melis, R., van Eijken, M., van Achterberg, T., Teerenstra, S., Vernooij-Dassen, M., van de Lisdonk, E. Marcel, G., & Rikkert, O. (2009). The effect on caregiver burden of a problem-based home visiting programme for frail older people. *Age and Ageing*, 38, 542-547. doi: 10.1093/ageing/afp101
- Mirza, M., Siebert, S., Pratt, A., Insch, E., McIntosh, F., Paton, J., Wright, C., Buckley, C., Isaacs, J., McInnes, I., Raza, k., & Falahee, M. (2021). Impact of the COVID-19 pandemic on recruitment to clinical research studies in rheumatology. *Musculoskeletal Care*, 1-5. doi: 10.1002/msc.1561.

- Möller-Leimkühler, A. & Wiesheu, A. (2012). Caregiver burden in chronic mental illness: the role of patient and caregiver characteristics. *European Archives of Psychiatry and Clinical Neuroscience*, 262, 157-166. doi: 10.1007/s00406-011-0215-5.
- Morland, L., Mackintosh, M., Rosen, C., Willis, E., Resick, P., Chard, K., & Freuh, C. (2015). Telemedicine versus in-person delivery of cognitive processing therapy for women with posttraumatic stress disorder: a randomized noninferiority trial. *Depression & Anxiety*, 32, 811-820. doi: 10.1002/da.22397.
- Muangpaisan, W., Matthews, A., Hori, H., & Seidel, D. (2011). A systematic review of the worldwide prevalence and incidence of Parkinson's disease. *Journal of the Medical Association of Thailand*, 94, 749-55.
- Munders, T., Wilmers, F., Leonhart, R., Linster, H., & Barth, J. (2010). Working Alliance Inventory Short Revised (WAI-SR): psychometric properties in outpatients and inpatients. *Clinical Psychology & Psychotherapy*, 17, 231-239. doi: 10.1002/cpp.658.
- Murphy, J., McKellar, J., Raffa, S., Clark, M., Kerns, R., & Karlin, B. (n.d.). *Cognitive behavioral therapy for chronic pain among veterans: therapist manual*. Washington, DC: U.S. Department of Veterans Affairs.
- National Institute on Aging, National Institutes of Health, & U.S. Department of Health and Human Services. (2015). *2014-2015 Alzheimer's disease progress report: advancing research toward a cure*. Retrieved from <https://www.nia.nih.gov/alzheimers/publication/2014-2015-alzheimers-disease-progress-report/introduction>
- National Institute on Aging. (2017, May 1). *What is respite care?* Retrieved from <https://www.nia.nih.gov/health/what-respite-care>

National Institute on Aging. (2020, September 23). *Telehealth: improving dementia care*.

Retrieved from: <https://www.nia.nih.gov/news/telehealth-improving-dementia-care>

Nichols, L., Chang, C., Lummus, A., Burns, R., Martindale-Adams, J., Graney, M., Coon, D., &

Czaja, S. (2008). The cost-effectiveness of a behavior intervention with caregivers of patients with Alzheimer's disease. *Journal of the American Geriatrics Society*, 56, 413-420. doi: 10.1111/j.1532-5414.2007.01569.x.

Noonan, A. & Tennstedt, S. (1997). Meaning in caregiving and its contribution to caregiver well-being. *The Gerontologist*, 37, 795-794.

Northeastern Ohio Universities Colleges of Medicine and Pharmacy. (n.d.). Twenty questions to help you challenge negative thoughts. Retrieved from [https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=2ahUKEwjajbm0utDmAhUVK80KHZjHAu8QFjAAegQIBBAC&url=https%3A%2F%2Fwww.mcgill.ca%2Fcounselling%2Ffiles%2Fcounselling%2F20\\_questions\\_to\\_challenge\\_negative\\_thoughts\\_0.pdf&usg=AOvVaw1GmfTvayOR2-6sJCwjoMyz](https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=2ahUKEwjajbm0utDmAhUVK80KHZjHAu8QFjAAegQIBBAC&url=https%3A%2F%2Fwww.mcgill.ca%2Fcounselling%2Ffiles%2Fcounselling%2F20_questions_to_challenge_negative_thoughts_0.pdf&usg=AOvVaw1GmfTvayOR2-6sJCwjoMyz)

Novak, M. & Guest, C. (1989). Application of a multidimensional caregiver burden inventory. *The Gerontologist*, 29, 798-803. doi: 10.1093/geront/29.6.798.

Oei, T. & Green, A. (2008). The Satisfaction with Therapy and Therapist Scale-Revised (STTS-R) for group psychotherapy: psychometric properties and confirmatory factor analysis. *Professional Psychology: Research & Practice*, 39, 435-442. doi: 10.1037/0735-7028.39.4.435.

Oken, B., Fonareva, I., Haas, M., Wahbeh, H., Lane, J., Zajdel, D., & Amen, A. (2010). Pilot controlled trial of mindfulness meditation and education for dementia caregivers. *Journal*

- of Alternative and Complementary Medicine*, 16, 1031-1038. doi: 10.1089/acm.2009.0733.
- Ong, C., Lee, E., & Twohig, M. (2018). A meta-analysis of dropout rates in acceptance and commitment therapy. *Behaviour Research & Therapy*, 104, 14-33. doi: 10.1016/j.brat.2018.02.004.
- Ornstein, K. & Gaugler, J. (2012). The problem with “problem behaviors”: a systematic review of the association between individual patient behavioral and psychological symptoms and caregiver depression and burden with the dementia patient-caregiver dyad. *International Psychogeriatrics*, 24, 1536-1552. doi: 10.1017/S1041610212000737.
- Orsmond, G. & Cohn, S. (2015). The distinctive features of a feasibility study: objectives and guiding questions. *OTJR: Occupation, Participation & Health*, 1-9. Doi: 10.1177/1539449215578649.
- Ostwald, S., Hepburn, K., Caron, W., Burns, T., & Mantell, R. (1999). Reducing caregiver burden: a randomized psychoeducational intervention for caregivers of persons with dementia. *The Gerontologist*, 39, 299-309.
- Pagán-Ortiz, M., Cortés, D., Rudloff, N., Weitzman, P., & Levkoff, S. (2014). Use of an online community to provide support to caregivers of people with dementia. *Journal of Gerontology & Social Work*, 57, 694-709. doi: 10.1080/01634372.2014.901998.
- Papastavrou, E., Kalokerinou, A., Papacostas, S., Tsangari, H., & Sourtzi, P. (2007). Caring for a relative with dementia: family caregiver burden. *Journal of Advanced Nursing*, 58, 446-457. doi: 10.1111/j.1365-2648.2007.04250.x.
- Park, J., Mogg, R., Smith, G., Nakimuli-Mpungu, E., Jehan, F., Rayner, C., Condo, J., Decloedt, E., Nachega, J., Reis, G., & Mills, E. (2021). How COVID-19 has fundamentally

- changed clinical research in global health. *Lancet Global Health*, 9, 711-720. doi: 10.1016/S2214-109X(20)30542-8.
- Patterson, B., Boyle, M., Kivlenieks, M., & Ameringen, M. (2016). The use of waitlists as control conditions in anxiety disorders research. *Journal of Psychiatric Research*, 83, 112-120. doi: 10.1016/j.jpsychires.2016.08.015.
- Pearlin, L., Mullan, J., Semple, S., & Skaff, M. (1990). Caregiving and the stress process: an overview of concepts and their measures. *The Gerontologist*, 30, 583-594.
- Peeters, A., Mullins, G., Becker, D., Orellana, L., & Livingston, P. (2020). COVID-19's impact on Australia's health research workforce. *Lancet (London, England)*, 396, 461-461.
- Perrin, P., Rybarczyk, B., Pierce, B., Jones, H., Shaffer, C., & Islam, L. (2020). Rapid telepsychology deployment during the COVID-19 pandemic: a special issue commentary and lessons from primary care psychology training. *Journal of Clinical Psychology*, 76, 1173-1185. doi: 10.1002/jclp.22969.
- Petersen, R. (2007). Clinical diagnosis of mild cognitive impairment. [PowerPoint]. Retrieved from <https://www.alz.washington.edu/NONMEMBER/SPR07/ronpete.pdf>
- Peterson, A. & Halstead, T. (1998). Group cognitive-behavior therapy for depression in a community setting: a clinical replication series. *Behavior Therapy*, 29, 3-18.
- Pimouguet, C., Lavaud, T., Dartigues, J., & Helmer, C. (2010). Dementia case management effectiveness on health care costs and resource utilization: a systematic review of randomized controlled trials. *The Journal of Nutrition, Health, and Aging*, 14, 669-676.
- Pinquart, M. & Sörensen, S. (2006). Helping caregivers of persons with dementia: which interventions work and how large are their effects? In *Database of Abstracts of Reviews*



*of Effects (DARE): Quality-Assessed Reviews*. York, UK: Centre for Reviews and Dissemination.

- Pisetsky, E., Durkin, N., Crosby, R., Berg, K., Mitchell, J., Crow, S., Wonderlich, S., & Peterson, C. (2015). Examination of early group dynamics and treatment outcome in a randomized controlled trial of group cognitive behavior therapy for binge eating disorder. *Behaviour Research & Therapy*, 73, 75-78. doi: 10.1016/j.brat.2015.07.013.
- Population Reference Bureau (28 May 2020). The demography of dementia and dementia caregiving. Retrieved from: <https://www.prb.org/resources/the-demography-of-dementia-and-dementia-caregiving/>
- Quinn, C., Nelis, S., Martyr, A., Victor, C., Morris, R., & Clare, L. (2019). Influence of positive and negative dimensions of dementia caregiving on caregiver well-being and satisfaction with life: findings from the IDEAL study. *American Journal of Geriatric Psychiatry*, 27, 838-848. doi: 10.1016/j.jagp.2019.02.005.
- Rabey, J. & Dobrenovsky, E. (2016). Repetitive transcranial magnetic stimulation (rTMS) combined with cognitive training is a safe and effective modality for the treatment of Alzheimer's disease: clinical experience. *Journal of Neural Transmission*, 123, 1449-1455. doi:10.1007/s00702-016-1606-6.
- Rantakangas, K. & Halonen, R. (2020, August). Special needs of elderly in using web-based services. In *International Conference on Well-Being in the Information Society*, 50-60.
- Reid, J. & Finesinger, J. (2006). The role of insight in psychotherapy. *The American Journal of Psychiatry*, 108, 726-734. doi: 10.1176/ajp.108.10.726.

- Reidel, O., Klotsche, J., & Wittchen, H. (2016). Overlooking informal dementia caregivers' burden. *Research in Gerontological Nursing*, 9, 167-174. doi: 10.3928/19404921-20160531-02.
- Richardson, S., Carrol, C., Close, J., Gordon, A., O'Brien, J., Quinn, T., Rochester, L., Sayer, A., Shenkin, S., Velde, N., Woo, J., & Witham, M. (2020). Research with older people in a world with COVID-19: identification of current and future priorities, challenges and opportunities. *Age and Ageing*, 49, 901-906. doi: 10.1093/ageing/afaa149.
- Röhrle, B. & Strouse, R. (2008). Influence of social support on success of the therapeutic interventions: a meta-analytic review. *Psychotherapy*, 45, 464-476. doi: 10.1037/a0014333.
- Rizzi, L., Rosset, I., & Roriz-Cruz, M. (2014). Global epidemiology of dementia: Alzheimer's and vascular types.
- Robinson, K., Adkisson, P., & Weinrich, S. (2001). Problem behaviour, caregiver reactions, and impact among caregivers of persons with Alzheimer's disease. *Journal of Advanced Nursing*, 36, 573-582.
- Rosenbaum, M., Friedlander, J., & Kaplan, S. (1956). Evaluation of results of psychotherapy. *Psychosomatic Medicine*, 18, 113-132.
- Sallim, A., Sayampanathan, A., Cuttilan, A., & Ho, R. (2015). Prevalence of mental health disorders among caregivers of patients with Alzheimer disease. *Journal of the American Medical Directors Association*, 16, 1034-1041. doi: 10.1016/j.jamda.2015.09.007.
- Sathian, B., Asim, M., Banerjee, I., Pizarro, A., Roy, B., Teijlingen, E., Nascimento, I., & Alhamad, H. (2020). Impact of COVID-19 on clinical research: a systematic review. *Nepal Journal of Epidemiology*, 10, 878-887. doi: 10.3126/nje.v10i3.31622.

- Savundranayagam, M. & Montgomery, R. (2010). Impact of role discrepancies on caregiver burden among spouses. *Research on Aging*, 32, 175-199. doi: 10.1177/0164027509351473.
- Savundranayagam, M., Montgomery, R., & Kolsoski, K. (2010). A dimensional analysis of caregiver burden among spouses and adult children. *The Gerontologist*, 51, 321-331. doi: 10.1093/geront/gnq102.
- Saykin, A. & Rabin, L. (2014). Dementias and Neurodegenerative Diseases. In M. W. Parsons and T. A. Hammeke (Eds.), *Clinical neuropsychology: a pocket handbook for assessment* (237-265). Washington, DC: American Psychological Association.
- Schoenwald, S. & Garland, A. (2013). A review of treatment adherence measurement methods. *Psychological Assessment*, 25, 146-156. doi: 10.1037/a0029715.
- Scott, J., Dawkins, S., Quinn, M., Sanderson, K., Elliot, K., Stirling, C., Schüz, B., & Robinson, A. (2016). Caring for the carer: a systematic review of pure technology-based cognitive behavioral therapy (TB-CBT) interventions for dementia carers. *Aging & Mental Health*, 20, 793-803. doi: 10.1080/13607863.2015.1040724.
- Secker, D. & Brown, R. (2004). Cognitive behavioural therapy (CBT) for carers of patients with Parkinson's disease: a preliminary randomized controlled trial. *Journal of Neurology, Neurosurgery, & Psychiatry*, 72, 491-497.
- Segal, Z. & Walsh, K. (2016). Mindfulness based cognitive therapy for residual depressive symptoms and relapse prophylaxis. *Current Opinions in Psychiatry*, 29, 7-12. doi: 10.1097/YCO.0000000000000216.

- Shaji, K., George, R., Prince, M., & Jacob, K. (2009). Behavioral symptoms and caregiver burden in dementia. *Indian Journal of Psychiatry*, 51, 45-49. doi: 10.4103/0019-5545.44905.
- Shanley, C. (2006). Developing more flexible approaches to respite for people living with dementia and their carers. *American Journal of Alzheimer's Disease & Other Dementias*, 21, 234-241. doi: 10.1177/1533317506290446.
- Shapiro, S., Carlson, L., Astin, J., & Freedman, B. (2006). Mechanisms of mindfulness. *Journal of Clinical Psychology*, 62, 373-386. doi: 10.1002/jclp.20237.
- Shaw, C., McNamara, R., Abrams, K., Cannings-John, R., Hood, K., Longo, M., Myles, S., O'Mahony, S., Roe, B., & Williams, K. (2009). Systematic review of respite care in the frail elderly. *Health Technology Assessment*, 13(20), 1-224.
- Shepherd-Banigan, M., McDuffie, J., Shapiro, A., Brancu, M., Sperber, N., Metha, N., & Williams, J. (2018). *Interventions to support caregivers or families of patients with TBI, PTSD, or polytrauma: a systematic review*. Retrieved from Department of Veterans Affairs, Veterans Health Administration, Quality Enhancement Research Initiative, Health Services Research & Developmental Service:  
<http://www.hsrd.research.va.gov/publications/esp/reports.cfm>
- Sheskin, D. (2011). *Handbook of Parametric and Nonparametric Statistical Procedures, Fifth Edition*. Boca Raton, FL: Chapman and Hall CRC.
- Skeer, M., Yantsides, K., Eliasziw, M., Carlton-Smith, A., Tracy, M., & Spirito, A. (2016). Testing a brief substance misuse preventive intervention for parents of pre-adolescents: feasibility, acceptability, preliminary efficacy. *Journal of Child & Family Studies*, 25, 3739-3749. doi: 10.1007/s10826-016-0525-3.

- Song, H., Lynch, M., & Cochran, J. (2015). A macro-social exploratory analysis of the rate of interstate cyber-victimization. *American Journal of Criminal Justice*, *41*, 583-601. doi: 10.1007/z12109-015-9308-4.
- Steketee, G. (1993). Social support and treatment outcome of obsessive compulsive disorder at 9-month follow-up. *Behavioural & Cognitive Psychotherapy*, *21*, 81-95. doi: 10.1017/S014134730001805X.
- Stewart, A., Nápoles, A., Piawah, S., Santoyo-Olsson, J., & Teresi, J. (2020). Guidelines for evaluating the feasibility of recruitment in pilot studies of diverse populations: an overlooked but important component. *Ethnicity & Disease*, *30*, 745-754. doi: 10.18865/ed.30.S2.745.
- Stiens, G., Maeck, L., & Stoppe, G. (2006). Filial maturity as a predictor of the burden of demented parents' caregivers. *Alzheimer Disease & Associated Disorders*, *18*, 99-109.
- Stiles-Shields, C., Plevinsky, J., Psihogios, A., & Holmbeck, G. (2020). Considerations and future directions for conducting clinical research with pediatric populations during the COVID-19 pandemic. *Journal of Pediatric Psychology*, *45*, 720-724. doi: 10.1093/jpepsy/jsaa055.
- Strujo, E., Sanders, M., Fiscella, K., Thomas, M., Johnson, B., Deets, A., Lucas, C., Holder, T., Johal, N., Luque, A., Cassells, A., Williams, S., & Tobin, J. (2020). COVID-19 impact on multi-site recruitment and enrollment. *Society for Clinical Trials*, *17*, 501-504. doi: 10.1177/1740774520946270.
- Tang, B., Harary, E., Kurzman, R., Mould-Quevedo, J., Pan, S., Yang, J., & Qiao, J. (2013). Clinical characterization and the caregiver burden of dementia in China. *Value in Health Regional Issues*, *2*, 118-126. doi: 10.1016/j.vhri.2013.02.010.

- Tate, D., Valle, C., Crane, M., Nezami, B., Samuel-Hodge, C., Hatley, K., Diamond, M., & Polzien, K. (2017). Randomized trial comparing group size of periodic in-person sessions in a remotely delivered weight loss intervention. *International Journal of Behavioral Nutrition & Physical Activity*, *14*, 144. doi: 10.1186/s12966-017-0599-3.
- Taube-Schiff, M., Suvak, M., Antony, M., Beiling, P., & McCabe, R. (2007). Group cohesion in cognitive-behavioral group therapy for social phobia. *Behaviour Research & Therapy*, *45*, 687-698. doi: 10.1016/j.brat.2006.06.004.
- Thimm, J. & Antonsen, L. (2014). Effectiveness of cognitive behavioral group therapy for depression in routine practice. *BMC Psychiatry*, *14*, 292-300. doi: 10.1186/s12888-014-029-x
- Thrasher, S., Power, M., Morant, N., Marks, I., & Dalgleish, T. (2010). Social support moderates outcome in a randomized controlled trial of exposure therapy and (or) cognitive restructuring for chronic posttraumatic stress disorder. *Canadian Journal of Psychiatry*, *55*, 187-190.
- Tickle-Degnen, L. (2013). Nuts and bolts of conducting feasibility studies. *The American Journal of Occupational Therapy*, *67*, 171-176. Doi: 10.5014/ajot.2013.006270.
- Torti, F., Gwyther, L., Reed, S., Friedman, J., & Schulman, K. (2004). A multinational review of recent trends and reports in dementia caregiver burden. *Alzheimer Disease and Associated Disorders*, *18*, 99-109. doi: 10.1097/01.wad.0000126902.37908.b2.
- Toseland, R., Labrecque, M., Goebel, S., & Whitney, M. (1992). An evaluation of a group program for spouses of frail elderly veterans. *The Gerontologist*, *32*, 382-390.

Trachtenberg, L., Wong, J., Rennie, H., McLeod, D., Leung, Y., Warner, E., & Esplen, M.

(2019). Feasibility and acceptability of i-Restoring Body Image after Cancer (i-ReBIC): a pilot trial for female cancer survivors. *Psycho-Oncology*, 29, 639-646.

Tremont, G., Davis, J., Bishop, D., & Fortinsky, R. (2008). Telephone-delivered psychosocial intervention reduces burden in dementia caregivers. *Dementia*, 7, 503-520. doi: 10.1177/1471301208096632.

Truzzi, A., Valente, L., Ulstein, I., Engelhardt, E., Laks, J., & Engedal, K. (2012). Burnout in familial caregivers of patients with dementia. *Journal of the Brazilian Psychiatric Association*, 34, 405-412. doi: 10.1016/j.rbp.2012.02.006.

Tucker, M. & Oei, T. (2007). Is group more cost effective than individual cognitive behaviour therapy? The evidence is not solid yet. *Behavioural & Cognitive Psychotherapy*, 35, 77-91. doi: 10.1017/S1352465806003134.

UyBico, S., Pavel, S., & Gross, C. (2006). Recruiting vulnerable populations into research: a systematic review of recruitment interventions. *Society of General Internal Medicine*, 22, 852-863. doi: 10.1007/s11606-007-0126-3.

United States Department of Health and Human Services. (2003, August 1). *A compendium of intervention and descriptive studies designed to promote the health of caregivers for older adults. REACH II: resources for enhancing Alzheimer's caregiver health*. Retrieved from <https://aspe.hhs.gov/report/compendium-intervention-and-descriptive-studies-designed-promote-health-caregivers-older-adults/reach-ii-resources-enhancing-alzheimers-caregiver-health>

Vandepitte, S., Noortgate, N., Putman, K., Verhaeghe, S., Verdonck, C., & Annemans, L.

(2016). Effectiveness of respite care in supporting informal caregivers of persons with

- dementia: a systematic review. *International Journal of Geriatric Psychiatry*, 31, 1277-1288. doi: 10.1002/gps.4504.
- Vowles, K., Wetherell, J., & Sorrell, J. (2009). Targeting acceptance, mindfulness, and values-based action in chronic pain: findings of two preliminary trials of an outpatient group-based intervention. *Cognitive & Behavioral Practice*, 16, 49-58. doi: 10.1016/j.cbpra.2008.08.001.
- Walters, S., Henriques-Cadby, I., Bortolami, O., Flight, L., Hind, D., Jacques, R., Knox, C., Nadin, B., Rothwell, J., Surtees, M., & Julious, S. (2017). Recruitment and retention of participants in randomized controlled trials: a review of trials funded and published by the United Kingdom Health Technology Assessment Programme. *BMJ Open*, 7, 1-10. doi: 10.1136/bmjopen-2016-015276.
- Watson, C., Tuorila, J., Vickers, K., Gearhart, L., & Mendez, C. (1998). The efficacies of three relaxation regimens in the treatment of PTSD in Vietnam war veterans. *Journal of Clinical Psychology*, 53, 917-923. doi: 10.1002/(SICI)1097-4679(199712)53:8<917::AID-JCLP17>3.0.CO;2-N
- Webber, K., Tate, D., & Quintiliani, L. (2008). Motivational interviewing in internet groups: a pilot study for weight loss. *Journal of the American Dietetic Association*, 108, 1029-1032. doi: 10.1016/j.jada.2008.03.005.
- Westbrook, D. & Kirk, J. (2005). The clinical effectiveness of cognitive behaviour therapy: outcome for a large sample of adults treated in routine practice. *Behaviour Research & Therapy*, 43, 1243-1261.
- Whitcomb, S., Harlacher, J., & Merrell, K. (2014). *Chapter 7: Behavioral rating scales* (R. Archer & S. Smith, Eds). Routledge: New York, NY.



- Wimo, A. & Winblad, B. (2003). Pharmacoeconomics of mild cognitive impairment. *Acta Neurol Scand*, 107, 94-99.
- World Health Organization. (2015). The epidemiology and impact of dementia: current state and future trends (WHO Report No. 15.3). Retrieved from [http://www.who.int/mental\\_health/neurology/dementia/en/](http://www.who.int/mental_health/neurology/dementia/en/)
- Yalom, I. & Leszcz, M. (2005). *The theory and practice of group psychotherapy*, 5<sup>th</sup> edition. New York, NY: Basic Books.
- Yoo, R., Yeom, J., Kim, G., Park, H., Kang, Y., Hwang, J., Choi, S., Na, H., Cho, S., Yu, K., Kim, D., Lee, J., & Jeong, J. (2019). A multicenter, randomized clinical trial to assess the efficacy of a therapeutic intervention program for caregivers of people with dementia. *Journal of Clinical Neurology*, 15, 235-242. doi: 10.3988/jcn.2019.15.2.235.
- Zarit, S., Gaugler, J., & Jarrott, S. (1999). Useful services for families: research findings and directions. *International Journal of Geriatric Psychiatry*, 14, 165-181.
- Zarit, S., Stephens, M., Townsend, A., & Greene, R. (1998). Stress reduction for family caregivers: effects of adult day care use. *Journal of Gerontology: Social Sciences*, 53, 267-277.
- Zerwas, S., Watson, H., Hofmeier, S., Levine, M., Hamer, R., Crosby, R., Runfola, C., Peat, C., Shapiro, J., Zimmer, B., Moessner, M., Kordy, H., Marcus, M., & Bulik, C. (2016). CBT4BN: a randomized controlled trial of online chat and face-to-face group therapy for bulimia nervosa. *Psychotherapy & Psychosomatics*, 86, 47-53. doi: 10.1159/000449025.
- Zigmond, A. & Snaith, R. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67, 361-370.

Zorowitz, R., Gillard, P., & Brainin, G. (2013). Poststroke spasticity: sequelae and burden on stroke survivors and caregivers. *Neurology*, 80, 45-52. doi:

10.1212/WNL.0b013e3182764c86.

## **APPENDIX A: INFORMED CONSENT FORM**

### ***Subject Consent Form***

*Eastern Virginia Medical School (EVMS) Institutional Review Board*

STUDY TITLE

ONLINE GROUP THERAPY FOR CAREGIVER BURDEN FOR DEMENTIA CAREGIVERS: A PILOT STUDY

### **Key Summary of Information**

We are inviting you to take part in a research study about caregiver stress and burden and ways to alleviate that stress in group-based therapy. This page is intended to provide you with key information to help you decide whether or not to participate. The detailed consent form follows this page. Please ask the research team questions. If you have questions later, the contact information for the principal investigator in charge of this study is below.

#### **WHAT IS THE PURPOSE, WHAT ARE THE PROCEDURES, AND WHAT IS THE DURATION OF THIS STUDY?**

The purpose of this study is to investigate an active, online intervention with cognitive behavioral therapy for caregivers of persons with dementia to decrease level of burden, stress, anxiety, and depression.

Caregivers will participate in a phone appointment during which the research study will be explained and eligibility will be determined. Following this, participants will sign an electronic informed consent form and complete additional survey measures about anxiety, burden, stress, and mood as well as demographic information.

The duration of the study will be 8 weeks.

#### **WHAT ARE SOME REASONS YOU MIGHT CHOOSE TO PARTICIPATE IN THIS STUDY?**

You may want to participate in this study in order to utilize a new online therapeutic technique that may help with your own anxiety, depression, and burden you are experiencing as a caregiver. You may also want to participate in this study in order to help demonstrate that this intervention may be beneficial to other caregivers in the future.

#### **WHAT ARE SOME REASONS YOU MIGHT CHOOSE NOT TO PARTICIPATE IN THIS STUDY?**

There are no medical conditions that would contraindicate participation. Participation would only be limited by personal interest.

#### **DO YOU HAVE TO TAKE PART IN THIS STUDY?**

If you decide to take part in the study, it should be because you really want to volunteer for it. You will not lose any services, benefits, or rights you would normally have if you choose not to volunteer. You are free to withdraw from the study at any time.

#### **WHAT IF YOU HAVE QUESTIONS OR CONCERNS?**

For questions about the study, contact the investigator, Dr. Serina Neumann (757-446-5888).

For questions about your rights as a research participant, contact a member of the Institutional Review Board through the Institutional Review Board office at (757) 446-8423.

Please continue to the next page for detailed information about the study.

[page break]

#### STUDY TITLE

ONLINE GROUP THERAPY FOR CAREGIVER BURDEN FOR DEMENTIA CAREGIVERS: A PILOT STUDY

#### INVESTIGATORS

Dr. Serina Neumann, Ph.D., Professor of Psychiatry and Behavioral Sciences, EVMS  
Daniel Schaffer, M.S., Psychology Ph.D. Candidate, EVMS/ODU/NSU

#### WHY IS THIS STUDY BEING DONE?

The purpose of this study is to investigate the feasibility of a new, online group-based therapy modality for caregivers of persons with dementia and its ability to reduce levels of caregiver burden, anxiety, and depression.

#### WHY ARE YOU BEING ASKED TO TAKE PART?

You are being asked to participate in this research project because you are a caregiver of a patient with dementia.

This is a research study. This study includes only people who choose to take part. Please take your time to make your decision and feel free to ask any questions you might have.

#### WHAT ARE SOME IMPORTANT DETAILS ABOUT THIS STUDY?

Approximately 15 people will take part in this study. We will need you to be in the study for 3 assessments over an 8-week period.

#### WHEN SHOULD YOU NOT TAKE PART?

There are no medical conditions that would contra indicate participation. Participation would only be limited by personal interest.

#### WHAT IS INVOLVED IN THE STUDY?

You will undergo a phone session with a research administrator during which the research study will be explained and some preliminary questions may be asked to determine eligibility for participation. If interested and deemed eligible by a measure of caregiver burden, you will then be informed of the study's purposes and procedures – you will have the opportunity to have any of your questions answered. You will then sign an electronic informed consent form and complete online measures that will help measure anxiety, depression, and burden. You will be asked to complete these online measures

at 3 time points throughout this study: baseline (start-of-treatment), week 4 of treatment (mid-treatment), and end-of-treatment. You will also be asked to complete additional assessment measures asking about your experiences in the group therapy treatment at the end of the study.

The CBT group will meet online once per week for eight weeks and should contain between 4-8 participants. Group meetings will occur online via Bluejeans online meeting platform. There may be multiple treatment groups which may run concurrently or consecutively depending on timing of recruitment and group leader availability. Each session will be 60-minutes in duration, amounting to a total of eight hours of intervention. The assessment questionnaires will be re-administered at session four and at the end of session 8 to allow for start-of-treatment, mid-treatment and end-of-treatment measurements. Additional measures will be sent via email link three months after your completion of the 8-week treatment group to measure any maintenance of treatment-related changes. You will receive reminder phone calls to complete the assessments.

#### WHAT ARE THE RISKS OF THE STUDY?

There are very few known risks to you, beyond what we would normally expect from answering questions about your personal life and the time it takes to answer questionnaires; potential loss of confidentiality due to group discussions; and release of information on the survey instruments. At the beginning of group treatment, participants will be told not to discuss other caregivers outside of sessions. All participant survey information will be deidentified. Participants' names and contact information will be stored in a password protected document on a secure shared drive. There may be risks that are not yet known.

#### ARE THERE BENEFITS TO TAKING PART IN THE STUDY?

If you agree to take part in this study, there may or may not be direct benefit to you. There is no guarantee that you will personally benefit from taking part in this study. However, there may be a reduction in perceived stress, anxiety, and depression. We hope the information learned from this study will benefit other people who are caregivers of people with dementia in the future.

#### WHAT OTHER OPTIONS DO YOU HAVE?

You may choose not to participate in this research study

#### WHAT ABOUT CONFIDENTIALITY?

No protected health information will be used in this study. While the research administrators will take every precaution to protect the information and confidentiality of each research participant, the Bluejeans online meeting platform through which the online group therapy sessions will be conducted is not HIPAA compliant. Therefore, the researchers may not be able to completely guarantee that the information is completely secure. Only individuals who are participating in the group therapy sessions will be able to log-in and attend the Bluejeans online group sessions.

In the event a research administrator has reasonable cause to believe that a participant becomes a danger to him/herself or other individuals, the researchers may withdraw them from the study and inform emergency services. This would only be done after individual discussion and evaluation with the participant in-question to formally assess any potential for risk or harm.

#### WHAT WILL PARTICIPATION IN THE STUDY COST OR PAY?

There are no additional costs to you associated with taking part in this study.

#### WHAT ABOUT THE COLLECTION OF TISSUE/SPECIMENS?

You are in a study where identifiable survey and questionnaire results are collected as part of your participation in the research study. Right now, there are no plans to use the survey and questionnaire results for another research study. However, the identifiers might be removed and, after such removal, the survey and questionnaire results could be used for future research studies or distributed to another investigator for future research studies without additional informed consent from you or your legally authorized representative.

#### WHAT IF YOU GET INJURED?

Eastern Virginia Medical School will not provide free medical care for any sickness or injury resulting from being in this study. Financial compensation for a research related injury or illness, lost wages, disability, or discomfort is not available. However, you do not waive any legal rights by signing this consent form.

#### WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

Taking part in this study is your choice. If you decide not to take part, your choice will not affect any medical benefits to which you are entitled. You may choose to leave the study at any time. If you do leave the study, discuss it with the investigator who will help you do so in the safest way. If you leave the study it will not result in any penalty or loss of benefits to you.

The investigator may decide to take you off this study if you cancel your approval or if it negatively impacts your health.

We will tell you about new information that may affect your health, welfare, or willingness to stay in this study.

#### WHOM DO YOU CALL IF YOU HAVE QUESTIONS OR PROBLEMS?

For questions about the study, contact the investigator, Dr. Serina Neumann, at (757) 446-5888.

For questions about your rights as a research participant, contact a member of the Institutional Review Board through the Institutional Review Board office at (757) 446-8423.

If you believe you have suffered an injury as a result of your participation in this study, you should contact the principal investigator, *Dr. Serina Neumann* at (757) 446-5888. You may also contact Betsy Conner, director, EVMS Human Subjects Protection Program and IRB office at Eastern Virginia Medical School, at (757) 446-5854.

#### SIGNATURE

You will get a copy of this signed form. You may also request information from the investigator. By signing your name on the line below, you agree to take part in this study and accept the risks.

_____	_____	_____	____/____ /____ MM/ DD/ YY
Signature of Participant	Typed or Printed Name	Relationship to Subject	

#### STATEMENT OF THE INVESTIGATOR OR APPROVED DESIGNEE

I certify that I have explained to the above individual the nature and purpose of the study, potential benefits, and possible risks associated with participation in this study. I have answered any questions that have been raised and have witnessed the above signature. I have explained the above to the volunteer on the date stated on this consent form.

_____	____/____/____ MM/ DD/ YY
Signature of Investigator or Approved Designee	

## APPENDIX B: CAREVER BURDEN INVENTORY (CBI)

Adapted from Novak & Guest (1989).

Please rate each of the following items on a scale of 0-4 based on the frequency of each item  
(0 = *not at all*, 1 = *very little*, 2 = *moderately*, 3 = *much*, 4 = *very much*)

1. \_\_\_\_ My care receiver needs my help to perform many daily tasks.
2. \_\_\_\_ My care receiver is dependent on me.
3. \_\_\_\_ I have to watch my care receiver constantly.
4. \_\_\_\_ I have to help my care receiver with many basic functions.
5. \_\_\_\_ I don't have a minute's break from my caregiving chores.
6. \_\_\_\_ I feel that I'm missing out on life.
7. \_\_\_\_ I wish I could escape from this situation.
8. \_\_\_\_ My social life has suffered.
9. \_\_\_\_ I feel emotionally drained due to caring for my care receiver.
10. \_\_\_\_ I expected that things would be different at this point of my life.
11. \_\_\_\_ I'm not getting enough sleep.
12. \_\_\_\_ My health has suffered.
13. \_\_\_\_ Caregiving has made me physically ill.
14. \_\_\_\_ I am physically tired.
15. \_\_\_\_ I don't get along with other family members as well as I used to.
16. \_\_\_\_ My caregiving efforts aren't appreciated by others in my family.
17. \_\_\_\_ I've had problems with my marriage.
18. \_\_\_\_ I don't do as good a job at work as I used to.
19. \_\_\_\_ I feel resentful of other relatives who could but do not help.
20. \_\_\_\_ I feel embarrassed by my own care receiver's behavior.
21. \_\_\_\_ I feel ashamed of my care receiver.
22. \_\_\_\_ I resent my care receiver.
23. \_\_\_\_ I feel uncomfortable when I have friends over.
24. \_\_\_\_ I feel angry about my reactions toward my care receiver.

---

For administrator only – do not fill out this section.

1. \_\_\_\_ Time Dependent Burden Total (items 1-5)
2. \_\_\_\_ Developmental Burden Total (items 6-10)
3. \_\_\_\_ Physical Burden Total (items 11-14)
4. \_\_\_\_ Social Burden Total (items 15-19)
5. \_\_\_\_ Emotional Burden Total (items 20-24)
6. \_\_\_\_ Total Burden (all items total)



### APPENDIX C: HOSPITAL ANXIETY AND DEPRESSION SCALE (HADS)

Circle the number beside the reply that is closest to how you have been feeling in the past week.

D	A		D	A	
		<b>I feel tense or 'wound up':</b>			<b>I feel as if I am slowed down:</b>
	3	Most of the time	3		Nearly all of the time
	2	A lot of the time	2		Very often
	1	From time to time, occasionally	1		Sometimes
	0	Not at all	0		Not at all
		<b>I still enjoy the things I used to enjoy:</b>			<b>I get sort of frightened feeling like 'butterflies' in the stomach:</b>
0		Definitely as much	0		Not at all
1		Not quite so much	1		Occasionally
2		Only a little	2		Quite often
3		Hardly at all	3		Very often
		<b>I get a sort of frightened feeling as if something awful is about to happen:</b>			<b>I have lost interest in my appearance:</b>
	3	Very definitely and quite badly	3		Definitely
	2	Yes, but not too badly	2		I don't take as much care as I should
	1	A little, but it doesn't worry me	1		I may not take quite as much care
	0	Not at all	0		I take just as much care as ever
		<b>I can laugh and see the funny side of things:</b>			<b>I feel restless as I have to be on the move:</b>
0		As much as I always could	3		Very much indeed
1		Not quite so much now	2		Quite a lot
2		Definitely not so much now	1		Not very much
3		Not at all	0		Not at all
		<b>Worrying thoughts go through my mind:</b>			<b>I look forward with enjoyment to things:</b>
	3	A great deal of the time	0		As much as I ever did
	2	A lot of the time	1		Rather less than I used to
	1	From time to time, not too often	2		Definitely less than I used to
	0	Only occasionally	3		Hardly at all
		<b>I feel cheerful:</b>			<b>I get sudden feelings of panic:</b>
3		Not at all	3		Very often indeed
2		Not often	2		Quite often
1		Sometimes	1		Not very often
0		Most of the time	0		Not at all
		<b>I can sit at ease and feel relaxed:</b>			<b>I can enjoy a good book or radio or TV program</b>
	0	Definitely	0		Often
	1	Usually	1		Sometimes
	2	Not often	2		Not often
	3	Not at all	3		Very seldom

D = \_\_\_\_\_ A = \_\_\_\_\_

Source: Zigmond & Snaith, 1983

**APPENDIX D: ROLE CAPTIVITY SCALE (RCS)**

Here are some thoughts and feelings that people sometimes have about themselves as caregivers. Using the scale below, how much does each statement describe your thoughts about your caregiving? How much do you:

1 = Not at all

2 = Just a little

3 = Somewhat

4 = Very much

\_\_\_\_\_ 1. Wish you were free to lead a life of your own.

\_\_\_\_\_ 2. Feel trapped by your care-recipient's illness.

\_\_\_\_\_ 3. Wish you could just run away.

Total Role Captivity level = sum of all items: \_\_\_\_\_

Source: Pearlin et al., 1990

## APPENDIX E: SOCIAL PROVISIONS SCALE (SPS)

Adapted from Cutrona & Russell (1987).

**Instructions:** In answering the next set of questions, think about your experiences from the group sessions only – think about your interactions with other people who were in the group. Please tell me to what extent you agree that each statement describes your relationships with other people from the group sessions. Use the following scale to give your opinion. For example, if you feel a statement is very true of your current relationships, you would say “strongly agree.” If you feel a statement clearly does not describe your relationships at all, you would respond “strongly disagree.”

- |                       |              |           |                    |
|-----------------------|--------------|-----------|--------------------|
| 1 = Strongly Disagree | 2 = Disagree | 3 = Agree | 4 = Strongly Agree |
|-----------------------|--------------|-----------|--------------------|
- \_\_\_\_\_ 1. There were people that I could depend on to help me if I really need it.
  - \_\_\_\_\_ 2\*. I feel that I did not have close personal relationships with other people.
  - \_\_\_\_\_ 3\*. There was no one I could turn to for guidance in times of stress.
  - \_\_\_\_\_ 4. There were people who depended on me for help.
  - \_\_\_\_\_ 5. There were people who enjoyed the same social activities I do.
  - \_\_\_\_\_ 6\*. Other people did not view me as competent.
  - \_\_\_\_\_ 7. I felt personally responsible for the well-being of another person (i.e., other group members).
  - \_\_\_\_\_ 8. I felt part of a group of people who share my attitudes and beliefs.
  - \_\_\_\_\_ 9\*. I did not think other people respected my skills and abilities.
  - \_\_\_\_\_ 10\*. If something went wrong, no one would come to my assistance.
  - \_\_\_\_\_ 11. I had close relationships that provided me with a sense of emotional security and well-being.
  - \_\_\_\_\_ 12. There was someone I could talk to about important decisions in my life.
  - \_\_\_\_\_ 13. I had relationships where my competence and skills were recognized.
  - \_\_\_\_\_ 14\*. There was no one who shares my interests and concerns.
  - \_\_\_\_\_ 15\*. There was no one who really relied on me for their well-being.
  - \_\_\_\_\_ 16. There was a trustworthy person I could turn to for advice if I were having problems.
  - \_\_\_\_\_ 17. I felt a strong emotional bond with at least one other person.
  - \_\_\_\_\_ 18\*. There was no one I could depend on for aid if I really need it.
  - \_\_\_\_\_ 19\*. There was no one I felt comfortable talking about problems with.
  - \_\_\_\_\_ 20. There were people who admired my talents and abilities.
  - \_\_\_\_\_ 21\*. I lacked a feeling of intimacy with another person.
  - \_\_\_\_\_ 22\*. There was no one who likes to do the things I do.
  - \_\_\_\_\_ 23. There were people I could count on in an emergency.
  - \_\_\_\_\_ 24\*. No one needed me to care for them.

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Scoring (administrator use only)

Guidance = \_\_\_\_\_ (sum of items 3, 12, 16, 19)

Reassurance of Worth = \_\_\_\_\_ (sum of items 6, 9, 13, 20)

Social Integration = \_\_\_\_\_ (sum of items 5, 8, 14, 22)

Attachment = \_\_\_\_\_ (sum of items 2, 11, 17, 21)

Nurturance = \_\_\_\_\_ (sum of items 4, 7, 15, 24)

Reliable Alliance = \_\_\_\_\_ (sum of items 1, 10, 18, 23)

Total Social Support = \_\_\_\_\_ (sum of all items)

[\* = items are reverse-scored]

## APPENDIX F: THERAPEUTIC FACTORS INVENTORY, COHESION SUBSCALE (TFI-COH)

The following questions will ask you to focus on your experiences in group therapy. Use the following rating scale to respond to each of the following items:

- 1 = Not at all  
2 = A little bit  
3 = Somewhat  
4 = Moderately  
5 = Quite a bit  
6 = A great deal  
7 = Extremely

1. \_\_\_\_\_ Even though others may have disagreed with me sometimes, I felt accepted in group.
2. \_\_\_\_\_ We cooperated and worked together in group.
3. \_\_\_\_\_ I felt accepted by the group.
4. \_\_\_\_\_ \* The members distrusted each other.
5. \_\_\_\_\_ I felt a sense of belonging in this group.
6. \_\_\_\_\_ I felt good about being a part of this group.
7. \_\_\_\_\_ \* Group members did not express caring for one another.
8. \_\_\_\_\_ We trusted each other in my group.
9. \_\_\_\_\_ Even though we had differences, our group felt secure to me.

\* indicates reverse scored items

Total Cohesiveness score = sum of all items: \_\_\_\_\_

Source: Lese & MacNaire-Semands, 2000; Yalom & Leszcz, 2005

### APPENDIX G WORKING ALLIANCE INVENTORY, SHORT FORM (WAI-SF)

Please use the following scale to respond to each item based on your experiences in this therapy group.

1 = Never

2 = Rarely

3 = Occasionally

4 = Sometimes

5 = Often

6 = Very Often

7 = Always

1. \_\_\_\_\_ The therapist and I agreed about the things I needed to do in therapy to help me improve my situation.
2. \_\_\_\_\_ What I did in therapy gave me new ways of looking at my problem.
3. \_\_\_\_\_ I believe the therapist liked me.
4. \_\_\_\_\_ \* The therapist did not understand what I was trying to accomplish in therapy.
5. \_\_\_\_\_ I was confident in the therapist's ability to help me.
6. \_\_\_\_\_ The therapist and I were working towards mutually agreed upon goals.
7. \_\_\_\_\_ I felt that the therapist appreciated me.
8. \_\_\_\_\_ The therapist and I agreed on what was important for me to work on.
9. \_\_\_\_\_ The therapist and I trusted one another.
10. \_\_\_\_\_ \* The therapist and I had different ideas of what my problems were.
11. \_\_\_\_\_ The therapist and I had established a good understanding of the kind of changes that would be good for me.
12. \_\_\_\_\_ I believe the way we were working with my problems was correct.

\* indicates reverse scoring.

Collaboration on Task subscale = sum of items 1, 2, 8, and 12: \_\_\_\_\_

Agreement on Goal subscale = sum of items 3, 5, 7, and 9: \_\_\_\_\_

Affect Bond (patient-therapist) subscale = sum of items 4, 5, 10, and 11: \_\_\_\_\_

Total Working Alliance Scale = sum of all items: \_\_\_\_\_

Source: Munder et al., 2010

### APPENDIX H: GROUP ATTITUDE SCALE (GAS)

Using the following scale, please respond to each of the following items based on the extent to which you agree with each statement.

1 = Agree      2      3      4      5      6      7      8      9 = Disagree

1. \_\_\_\_\_ \* I wanted to remain a member of this group.
2. \_\_\_\_\_ \* I liked my group.
3. \_\_\_\_\_ \* I looked forward to coming to group sessions.
4. \_\_\_\_\_ I didn't care what happened in this group.
5. \_\_\_\_\_ \* I felt involved in what happens in this group.
6. \_\_\_\_\_ If I could have dropped out of the group, I would have.
7. \_\_\_\_\_ I dreaded coming to this group.
8. \_\_\_\_\_ I wish it were possible for the group to have ended earlier.
9. \_\_\_\_\_ I was dissatisfied with the group.
10. \_\_\_\_\_ If it were possible to move to another group, I would have done so.
11. \_\_\_\_\_ \* I felt included in the group.
12. \_\_\_\_\_ \* Despite individual differences, a feeling of unity existed in my group.
13. \_\_\_\_\_ \* Compared to other groups I know of, I felt my group was better than most.
14. \_\_\_\_\_ I did not feel a part of the group's activities.
15. \_\_\_\_\_ \* I felt it would have made a difference to the group if I were not there.
16. \_\_\_\_\_ \* If I were told my group would not meet on a scheduled meeting date, I would have felt badly.
17. \_\_\_\_\_ I felt distant from the group.
18. \_\_\_\_\_ \* It made a difference to me how this group turned out.
19. \_\_\_\_\_ I felt my absence would not have mattered to the group.
20. \_\_\_\_\_ I would not have felt badly if I had to miss a meeting of this group.

\* indicates reverse-scored items

Total attraction/engagement with group = sum of all items: \_\_\_\_\_

Source: Evans & Jarvis, 1986

**APPENDIX I: DEMOGRAPHICS QUESTIONNAIRE**

Please respond to the following questions to the best of your ability by selecting one response for each answer that best applies to you.

1. What is your age (years)? \_\_\_\_\_
2. What is your gender?
  - a. Male
  - b. Female
  - c. Transgender
  - d. Other (please specify) \_\_\_\_\_
3. What is your race?
  - a. Caucasian / White
  - b. African American / Black
  - c. Native American / American Indian
  - d. Asian / Asian American
  - e. Alaskan Native
  - f. Latino/a
  - g. Hawaiian / Pacific Islander
  - h. Multiracial (please specify) \_\_\_\_\_
  - i. Other (please specify) \_\_\_\_\_
4. Which statement best describes your current marital status?
  - a. Single, not married
  - b. Married
  - c. Separated
  - d. Divorced
  - e. Widowed
  - f. Other (please specify) \_\_\_\_\_
5. Which statement best describes your occupational employment status?
  - a. Employed, full time
  - b. Employed, part time
  - c. Retired
  - d. Disabled
  - e. Full-time caregiver
  - f. Otherwise not currently employed

6. What is the highest level of education you have obtained to this point?
- a. No schooling
  - b. Some high school, no diploma
  - c. High school diploma / GED
  - d. Some college, no degree
  - e. Technical / trade / vocational training
  - f. Associate's degree
  - g. Bachelor's degree
  - h. Master's degree
  - i. Professional degree
  - j. Doctoral degree
7. Please select the range that best describes your current household income:
- a. Less than \$20,000
  - b. \$20,000 - \$29,999
  - c. \$30,000 - \$49,999
  - d. \$50,000 - \$74,999
  - e. \$75,000 - \$99,999
  - f. \$100,000 - \$124,999
  - g. \$125,000 - \$149,999
  - h. \$150,000 - \$174,999
  - i. \$175,000 - \$199,999
  - j. \$200,000 or more
  - k. Prefer not to say
8. Do you have children (under the age of 18) currently living with you? If yes, please include how many:
- a. No
  - b. Yes \_\_\_\_\_
9. Does your care recipient currently live with you? [or] Do you currently live with your care recipient?
- a. No
  - b. Yes



10. Please select the response that best describes your relationship with your care recipient:

- a. He/She is my father/mother
- b. He/She is my spouse/significant other
- c. He/She is my grandfather/grandmother
- d. He/She is my great grandfather/great grandmother
- e. He/She is my brother/sister
- f. He/She is my son/daughter
- g. He/She is my uncle/aunt
- h. He/She is my nephew/niece
- i. He/She is my cousin
- j. He/She is a family member by-law
- k. Other (please specify) \_\_\_\_\_

11. How long (in years) have you identified as a primary caregiver for someone with dementia?

- a. Less than 1 year
- b. 1-2 years
- c. 3-5 years
- d. 6-10 years
- e. 11-15 years
- f. More than 15 years

12. Approximately how many hours per week do you spend providing care to your care-recipient? \_\_\_\_\_

13. Are you currently receiving individual psychotherapeutic or counseling services to help manage stress, anxiety, or depression?

- a. No
- b. Yes

14. Are you currently taking any prescribed medications on a regular basis to help manage stress, anxiety, or depression?

- a. No
- b. Yes (if yes, please list) \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## APPENDIX J: SCREENING QUESTIONNAIRE

These questions are to be asked to each caregiver at the time of the phone screening appointment. In order to be eligible to participate in this research study, all potential participants must meet all eligibility criteria. Any caregivers who do not meet the following criteria will not be eligible to participate in this research study.

1. Are you between the ages of 18 and 85 years old?
  - a. Yes [*continue to question 2*]
  - b. No [*discontinue – not eligible to participate*]
2. Do you consider yourself to be the primary caregiver for a person with mild cognitive impairment (MCI) or dementia?
  - a. Yes [*continue to question 3*]
  - b. No [*discontinue – not eligible to participate*]
3. Is your care-recipient currently enrolled in a long-term care facility?
  - a. Yes [*discontinue – not eligible to participate*]
  - b. No [*continue to question 4*]
4. Do you utilize on a regular basis any respite care services, such as at home nursing care or adult daycare?
  - a. Yes [*if yes, continue to question 5*]
  - b. No [*if no, skip question 5 and continue to question 6*]
5. Do you use respite services for a total of more than 10 hours per week?
  - a. Yes [*discontinue – not eligible to participate*]
  - b. No [*continue to question 6*]
6. Is your care-recipient a direct family member of yours including, but not limited to, parent, child, spouse or partner, sibling, aunt or uncle, niece or nephew, grandparent, or family member by-law?
  - a. Yes [*continue to question 7*]
  - b. No [*discontinue – not eligible to participate*]
7. Do you have reliable access to stable internet connection and a webcam, either via a desktop computer, laptop computer, smartphone, tablet, or other electronic device?
  - a. Yes [*administer CBI*]
  - b. No [*discontinue – not eligible to participate*]

Did the caregiver have a total score of 36 or greater on the Caregiver Burden Inventory (CBI)?

- a. Yes [*inquire about schedule availability for treatment groups*]
- b. No [*discontinue – not eligible to participate*]

Is the caregiver available to participate in at least one cognitive behavioral therapy group time, and are they able to set aside 1 hour/week in a room with little-to-no distractions to attend?

- a. Yes [*participant is eligible – collect and confirm email address to send baseline questionnaires and online consent form*] \_\_\_\_\_
- b. No [*discontinue – not eligible to participate*]

## APPENDIX K: CBT SESSION ONE

*[Baseline measures should be completed before the start of session 1: CBI, HADS, RCS, Demographics]*

### Introduction

At the start of session one, the facilitator should discuss limits of confidentiality.

The facilitator of the group should go over rules of group therapy interactions. Some of these rules can include, but are not limited to:

- Safe environment – all group members should be respectful of each other. No one should feel intimidated or put down at any point.
- Confidentiality by group members – group members should not discuss outside the group what group members say during group sessions. Everything that is said in group should stay in group.
- Absences and cancellations – group members should notify the EVMS outpatient psychology/psychiatry front desk staff if they are unable to attend a group session. The investigators understand that things may come up and emergencies can happen. If any of these things do happen, please inform the investigators ahead of time.
- Have an open mind – understand that everyone comes from different walks of life. What works for one person may not work for other people. Feel free to share experiences, and please refrain from putting other people down or making judgments.
- Be respectful of the group's time – this group only meets for a limited time, and everyone should have the opportunity to share if they so wish. Please feel free to share experiences, but avoid doing so in a way that prevents others from being able to share.
- Please avoid offensive language.
- Please be on time.
- These sessions are for the caregivers – caregivers should not bring their care-recipient to sessions (this remains true if the treatment is being administered online – participants should ensure that they have 60 minutes of available time during which they can attend the online session without their care-recipient). This is to allow open and honest discussion of caregiving-related stressors that each caregiver may be experiencing.
- Drinks (non-alcoholic) are okay as long as they have a lid/cap, but avoid bringing food to group meetings (unless medically required). (note: if sessions are administered online, any non-alcoholic beverage may be permitted regardless of lid/cap, but participants should still refrain from eating food during session unless medically required).

After the rules have been explained, everyone should have the opportunity to ask questions and pose additional rules to the group for discussion. The facilitator should allow everyone to introduce themselves to the group. If the group members feel comfortable, they should also state how long they've been a caregiver for someone with dementia.

The facilitator should then provide an overview of the treatment plan: this group is not going to focus too much on education about dementia and the disease progression. Instead, this group is designed to help cope with the physical and psychological stress that comes with caring for

someone with dementia. By taking better care of yourself, you as caregivers will be able to provide better care to your care-recipient – you can't take care of others without taking care of yourself.

Caregiver burden = the overall impact of the physical, psychological, social, and financial demands of caregiving. This often arises among people providing care for individuals with chronic illnesses, including dementia. Unpaid caregivers provide an average of 21.9 of unpaid care per caregiver per week – the equivalent of a second part-time job.

Family caregivers report increased stress/strain, and over 1/3 of family caregivers report elevated levels of depression.

### Caregiver Stress

Stress is defined as a state of mental or emotional strain/tension resulting from adverse or very demanding circumstances. Persistently high amounts of stress over long periods of time lead to burnout, which is a state of physical and mental collapse. Both stress and burnout can have detrimental effects both on physical and mental wellbeing.

The Alzheimer's Association identifies 10 symptoms of caregiver stress:

1. Denial --- denial about the disease and its effects.
2. Anger --- anger or frustration towards the person with dementia because they aren't able to perform tasks they used to be able to do easily.
3. Social Withdrawal --- withdrawing from friends and activities that were previously enjoyable.
4. Anxiety --- anxiety and worry about the future.
5. Depression --- depressed mood that makes it even more difficult to cope with the day-to-day stressors.
6. Exhaustion --- the feeling that it is nearly impossible to perform daily tasks because of feeling too tired or overwhelmed.
7. Sleeplessness --- sleep disturbances at night which ultimately makes individuals more prone to things like exhaustion.
8. Irritability --- mood fluctuations that lead to negative responses.
9. Difficulty Concentrating --- reductions in ability to focus on a single given task, or moments of forgetfulness.
10. Health Problems --- stress takes a physical toll such as feeling physically bad or falling ill.

Allow some time for the group to process and for open discussion:

- How many of these have group members experienced?
- What are certain things that trigger any of these symptoms?
- What situations cause a spike in stress level?

Hand out Caregiver Stress Checklist (see Appendix R) and provide instructions on how to complete it.

Homework for the coming week: Fill out Caregiver Stress Checklist

*[Provide quality metrics to each group member at the end of session four: SPS, TFI-Coh, WAI-SF, GAS. If sessions are online, send these assessments to participants immediately following the conclusion of this session – be sure to inform participants that they will be receiving them and to complete them as soon as possible.]*

**Overall purpose of this session:** To begin developing insight and awareness into one's experiences of caregiver burden. The act of tracking caregiver stress via the caregiver stress checklist will be a recurring task for patients/participants to continually build this insight/awareness, as well as provide an opportunity for caregivers to track their own subjective levels of change over treatment. By building insight from the start of treatment, further interventions in future sessions are likely to be more impactful, thus rendering the entire treatment more effective (Høglend & Hagtvét, 2019; Rosenbaum et al., 1956). Additionally, building insight into specific aspects of caregiver burden and related experiences for each group member will increase overall treatment effectiveness and promote movement towards change for the future sessions (Reid & Finesinger, 2006).

## APPENDIX L: CBT SESSION TWO

Brief review of last session (caregiver stress)

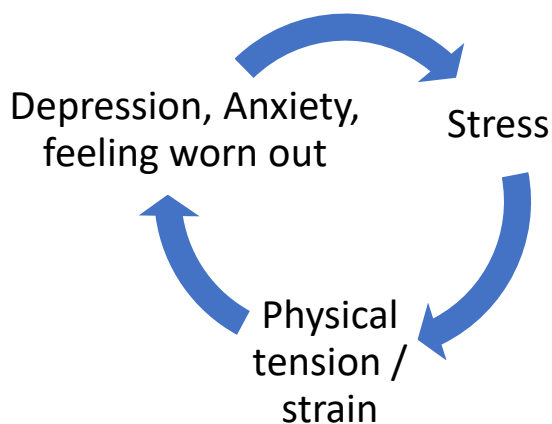
Check-In Procedure (10-15 minutes) – Discuss level of caregiver stress and highest daily rating.

### Relaxation Strategies

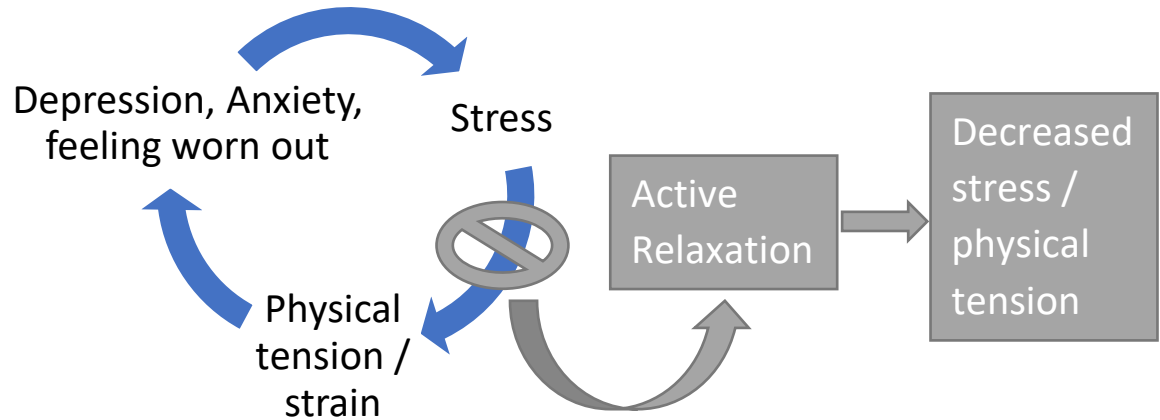
Start with a question: What does everyone do to relax?

A common misconception is that pleasant activities are the same as relaxation. And while some pleasant activities can have some relaxing effects (like watching TV, etc.), relaxation of your mind and body is in itself an active process, not passive. We'll talk more about pleasant activities next week, but this week our focus is going to be on active relaxation strategies.

Relaxation is really important, because caregiving can be a high-stress job. The prior session talked about signs of caregiver stress and how high levels of stress can lead to burnout and other physical illnesses, so managing stress by relaxation is going to help reduce overall stress level and reduce risk of burnout and falling ill.



High levels of mental stress can also lead to high levels of physical strain and tension, which can cause individuals to feel worn out both mentally and physically, and may even lead to things like anxiety and depression. By adding active relaxation techniques into one's routine, this breaks this cycle and starts to reduce one's overall level of stress and physical tension.



Relaxation Techniques (practice all if time is available, or just pick one to practice):

### *Deep Breathing*

The easiest and most fundamental active relaxation strategy is deep breathing. Most individuals are not mindful of their breathing. Sometimes, just taking a moment to take a few deep breaths from the diaphragm can reduce stress and tension in individuals' minds and bodies. Taking slow, deep breaths like this is almost like a "reset button" to the autonomic nervous system, which is the part of the nervous system that is in charge of anxiety and the fight/flight response.

When individuals do diaphragmatic breathing, they breathe into their stomachs. To help visualize it, put one hand on your chest and one hand on your stomach and practice breathing. The hand on your stomach should rise, while the hand on your chest should remain relatively still (or rise after your stomach). Breathe in slowly, hold for a few counts, and then slowly exhale.

Another way to walk someone through the deep breathing activity is the count-it-out 4-2-6 method: breath in slowly through the nose for 4 counts, hold for 2 counts, then slowly exhale through the mouth for 6 counts.

### *Progressive Muscle Relaxation (PMR)*

Progressive muscle relaxation, or PMR for short, is the process of going through one's body and consciously tensing all muscles and then releasing them one at a time. This typically either starts from the top (head) and works down (feet) or start from the bottom (feet) and work up (head).

Progressive muscle relaxation is beneficial because during stress, physical strain, and tension, muscles also enter a longer state of tension. When this happens, muscles can almost "forget" what it's like to be relaxed. By systematically tensing muscles, holding that tension for a few seconds, and then releasing it, this releases tension from the body and retrains the mind and body to recognize relaxation.

### *Guided Imagery*

Guided imagery is imagining a picture of a person, place, or thing that makes one feel relaxed or happy. This could be a stream, a mountain scene, dinner with family, etc. This technique doesn't just stop, though, at the image of the scene. Include all of your senses. For example, if imagining a beach, do you feel the breeze on your skin? Do you hear the sound of the waves breaking on the shore or the sound of birds flying overhead? Do you smell the ocean? Etc.

Guided imagery can be either guiding oneself through a familiar scene in one's mind's eye, or have an external voice walk through all of the steps (recommended). For an external guide, Youtube.com has plenty of videos for this, or download a smartphone app like Insight Timer with guided imagery videos as well.

For people with smartphones, there are some free apps (iOS and Android) that they can download to help with these active relaxation techniques outside of session:

- Breathe2Relax (just for guided deep breathing)
- Insight Timer (for deep breathing, guided imagery, progressive muscle relaxation; note: there is a subscription option with Insight Timer, but there are many resources through this application which are free to use)

Homework for the coming week:

- Continue with the Caregiver Stress Symptom Checklist.
- Practice at least one relaxation strategy each day.

**Overall purpose of this session:** To provide relaxation techniques that can help to break stress/strain cycles. By applying active relaxation techniques on a regular basis, caregivers can begin to lower their levels of physical stress/strain/tension which contribute to their overall levels of caregiver burden. Some of these relaxation strategies, such as deep breathing, can also be implemented in-the-moment when caregivers are faced with a particularly distressing experience, thus increasing their distress-tolerance (Kraemer et al., 2016).



## APPENDIX M: CBT SESSION THREE

Brief review of last session (relaxation strategies).

Check-In Procedure (10-15 minutes) – review homework. Go around the group and everyone should state how many symptoms of caregiver stress they experienced throughout the last week and the highest daily stress rating; discuss home-practice of relaxation strategies.

### Mindfulness

Mindfulness is the act of being mindful of one's surroundings and current environment. Often times, it is really easy to get “caught up in the buzz” of one's thoughts. Individuals constantly thinking about what happened earlier and all the different things that need to happen later. As a result, individuals often lose sight of the present moment.

When caught up in one's own thoughts, and focusing on too many things at once, it can often cause additional stress, tension, and anxiety. Mindfulness is a way to bring attention away from the many thoughts going through our minds at once and back to the present moment, thus reducing some of that stress and tension.

It's important to note that mindfulness is not just saying “don't think about this” or “don't let that thought enter my mind.” When we try to force ourselves not to think about something, it ultimately makes us think more and more about it (example: don't think about a pink elephant!). Instead, mindfulness acknowledges when one's mind wanders to various thoughts from the day, but doesn't place any judgment or weight to those thoughts so you can bring your attention gently back to the present moment.

Allow for some brief group discussion on this.

### Mindfulness Activity – Mindfulness of Breathing:

Begin by finding a comfortable position in your chair so that you can sit comfortably and allow yourself to be relaxed. [pause] You can close your eyes if that's what's comfortable for you, or you can leave them open with your eyelids relaxed. [pause] We'll start by taking a few deep breaths, breathing in through your nose, and out through your mouth. [pause] Breathe deeply in through your nose, and exhale slowly through your mouth. [pause] You can take a few more deep breaths, in through your nose and out through your mouth, to help allow yourself feel more relaxed and in this present moment. Then allow your breath to return to its normal pattern.

[pause] [pause] As we sit here, notice your breath. Simply notice the pattern of your breathing, breathing in and breathing out. Don't try to change the pattern of your breathing, simply notice the natural pattern of your breath. [pause] Notice how the breath feels – where do you feel the breath in your body. Maybe you feel it in your nostrils as you breathe in, or in the rise and fall of your chest. Simply take a moment to notice the feel of your breathing. [pause] [pause] As we do this exercise, you may notice thoughts running through your mind. That's okay, and that's perfectly normal. Simply notice those thoughts, and judging them or trying to change those thoughts, simply return your attention back to your breath in this present moment. [pause]

[pause] As you focus on your breath, and keeping your eye lids closed or relaxed, shift your attention to other areas in our present environment, and simply notice the here-and-now. [pause] [pause] What can you hear? Maybe the hum of the air conditioning, the ticking of a clock, maybe the low sound of people talking in conversation on the other end of the hallway. Take a moment to simply notice the sounds of the here-and-now. [pause] [pause] What sensations do you feel? Maybe it's the feel of your back against the chair, or your feet relaxed and touching the floor, or your hands or arms relaxed on the arms of the chair or on the table. What's the temperature like in the room? Is there a slight draft or breeze? Simply take a moment to notice the feel of the here-and-now. [pause] [pause] If your mind begins to wander away from the present moment, simply notice to where it wanders, and without judgment bring your attention back to the here-and-now. [pause] As we start to come to the end of this exercise, take another moment to notice anything else in the present moment – any sounds, any smells, any sensations. [pause] Take a deep breath, in through your nose, and slowly exhale through your mouth. When you're ready, you can open your eyes and come back to the present moment. [End]

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Allow for group discussion:

- What did everyone think of that exercise?
- Was it easy or difficult?
- What kind of thoughts did you notice popping into your head? What were the “loudest” thoughts?
- Was it hard to let go of your thoughts?
- Did doing that make you feel any better?

Mindfulness is surprisingly difficult. Our brains are hardwired and we are taught to be processing and thinking about multiple things at once. Unfortunately, this can be really counterintuitive to our overall wellbeing. By practicing mindfulness exercises like this, we can retrain our brains to focus more on the present moment, thus reducing our overall level of stress and tension.

Smartphone apps, like Insight Timer and Calm, can be great for helping you with mindfulness exercises – and they have free options (available for both iOS and Android devices).

Mindfulness doesn't have to just be in 5-10 minute exercises. The ultimate goal of mindfulness is to live a more mindful life, meaning always present in the present moment. As you get started, practice for a few minutes a day and then incrementally work your way up until you can adapt some of those mindfulness skills to other areas of life.

Homework for the coming week:

- Continue with the Caregiver Stress Symptom Checklist.
- Practice mindfulness for at least 5-10 minutes each day.

**Overall purpose of this session:** Adding mindfulness to the caregivers' repertoire of coping strategies will help to increase distress tolerance, increase coping abilities, and decrease their overall levels of enthrallment with caregiving related stressors. By detaching caregivers from

future-oriented and caregiving-related stressors, mindfulness has been shown to produce significant reductions in perceived levels of role captivity as well (Hagemann et al., 2019).

## APPENDIX N: CBT SESSION FOUR

Brief review of last session (mindfulness)

Check-In Procedure (10-15 minutes) – Discuss level of caregiver stress and highest daily rating; discuss mindfulness home practice and relaxation home practice.

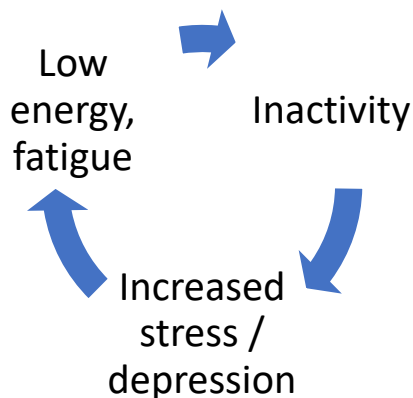
### Pleasant Activities

Two weeks ago, we discussed active relaxation strategies and how they are different from pleasant activities. Relaxation is the active process of releasing the tension from the body and mind. Pleasant activities provide enjoyment and positive distractions from stress.

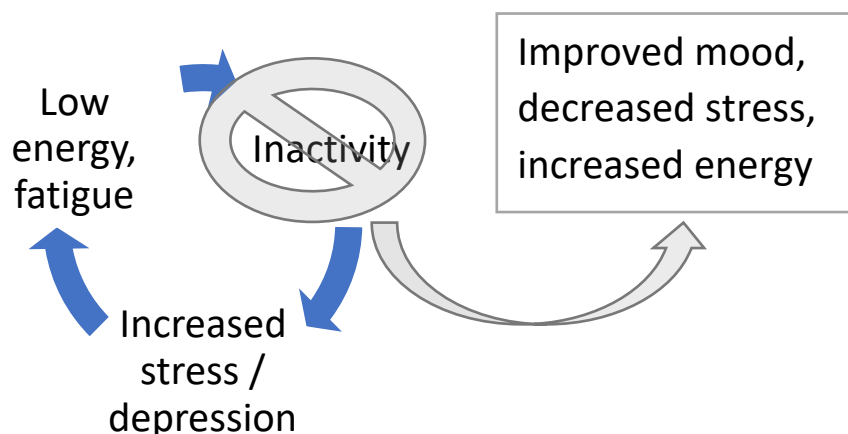
It is equally important to do pleasant activities for yourself, and also pleasant activities with loved ones if able.

What are some of the pleasant activities you may do for yourself?

What are some of the pleasant activities you may do with loved one(s)?



For both you and your care recipient, inactivity and stress/tension feed a vicious cycle. From one end, inactivity or avoiding participating in pleasant activities can lead to increased stress, tension, and even depression. From the other end, stress, tension, and depressed mood can lead to a lack of desire to participate in pleasant activities. As a result, further inactivity or withdrawal from pleasant activities further strengthens this negative cycle. However, this cycle can be broken by intervening at the level of activity. Making the commitment to actively engage in more pleasant activities can improve mood and decrease overall level of stress and tension.



It's important to engage in pleasant activities for yourself and also with your care recipient. This vicious cycle applies to them as well, so getting them engaged in things they enjoy may have a beneficial impact on their mood as well. Engaging in pleasant activities together can improve both of your moods, reduce stress/tension in both of you, reduce potential problematic behaviors, and strengthen the relationship and bond between you.

You'll want to make sure that any pleasant activities you engage in with your care recipient are safe for that person to participate in. Always make sure that safety is ensured.

### Barriers to Pleasant Activities

What are some things that might get in the way of doing any pleasant activities?

Time is a primary complaint for many people when they start planning for pleasant events. Being a caregiver is busy work, and day-to-day life may not always be as predictable as we would like. However, planning ahead and thinking about possible barriers, and how to overcome them should they come up, greatly improves the likelihood that we will be able to do what we set out to do.

Hand out Pleasant Activities Planning Sheet (see Appendix S).

Everyone think of one pleasant activity and fill out the part for Activity #1 on the Pleasant Activities Planning Sheet (Appendix S). Share with the group what the activity is, when you will plan on doing the activity, some potential barriers, and how you plan to overcome those barriers should they arise.

### Homework for the coming week:

- Continue with the Caregiver Stress Symptom Checklist.
- Plan at least two pleasant activities for the coming week – one for yourself, and one with your care recipient. Consider barriers to performing these and how to work around them.

*[Provide assessments to each group member at the end of session four: CBI, HADS, and RCS. If sessions are online, send these assessments to participants immediately following the conclusion of this session – be sure to inform participants that they will be receiving them and to complete them as soon as possible.]*

**Overall purpose of this session:** By instilling a schedule of pleasant activities, it further helps to (a) increase distress tolerance by breaking the physical stress/tension/strain cycles, (b) increases sense of agency within their personal lives (Dimidjian et al., 2011), and (c) increase sense of mastery and life satisfaction (Au et al., 2015). This sense of agency and mastery helps to further reduce the perceived level of role-captivity. In addition, planning for the potential “roadblocks” to the pleasant activities and problem-solving around them ahead of time is likely to increase the rate at which caregivers engage in pleasant activities for themselves, thus increasing the effectiveness of this intervention. In addition, incorporating behavioral activation immediately before the exploration of automatic thoughts and thinking patterns (see sessions five and six) allows for a targeted exploration of negative/maladaptive thoughts in the context of targeted behavior which may be contributing to experiences of burden (Dimidjian et al., 2011).

## APPENDIX O: CBT SESSIONS FIVE AND SIX

*Note for these sessions – Negative automatic thoughts and thought challenging has been broken up into two consecutive sessions. Session 5 should focus predominantly on the identification of negative automatic thoughts, while session 6 should continue with the challenging and reframing of those thoughts. During session 6, the facilitator may need to return to information provided during session 5 – this is okay and to be expected. These two sessions were grouped together because these two sessions go so closely together, and referencing back to session 5 will likely be very common during session 6. When applicable, the facilitator(s) should attempt to use examples of automatic thought identification/challenging posed by the patients / participants to increase the impact of the example(s) used.*

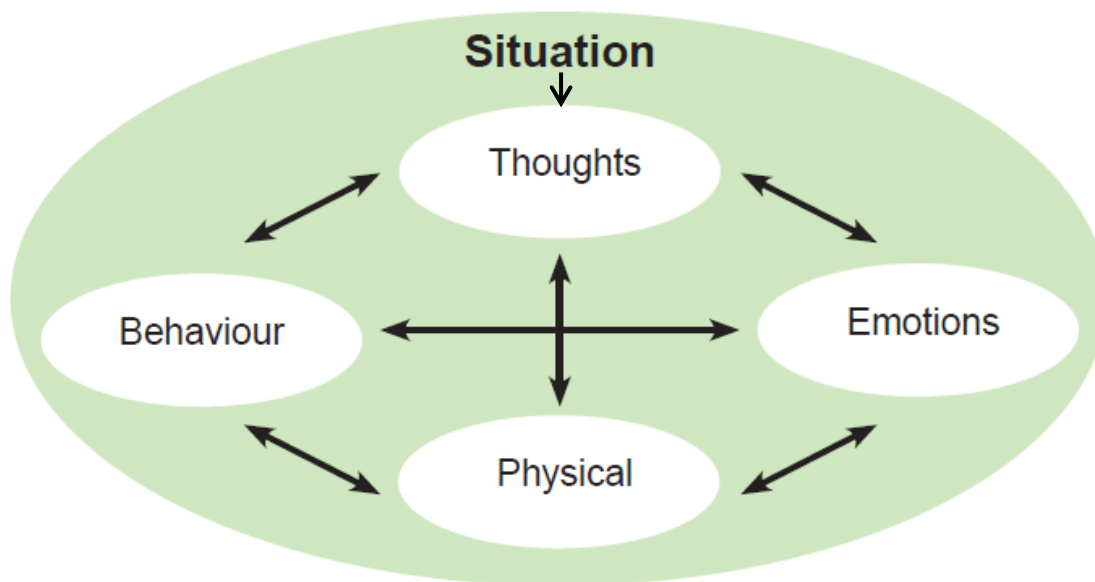
[Session 5] Brief review of last session (pleasant activities)

Check-In Procedure (10-15 minutes) – Discuss level of caregiver stress and highest daily rating; discuss pleasant activities home practice.

### Negative Automatic Thoughts

Our brains are constantly working. In fact, we do a lot of thinking without necessarily being consciously aware of it. Automatic thoughts are thoughts or images that pop into our head in an almost immediate response to a given situation. Sometimes we are aware of these thoughts, other times we may be less aware.

A common misconception is that situations directly cause an emotional response. In fact, the situation evokes an automatic thought which then creates the emotional, behavioral, and physiological responses:



In a given situation, we have an automatic thought response. These thought responses then influence how we feel physically, how we feel emotionally, and our resulting behavioral response. If we have a negative automatic thought in response to a situation, we are more likely

to experience negative emotions, negative physical feelings, and maladaptive behavioral responses.

Allow some time for the group to process/discuss this as needed.

Ask the group: Are our thoughts always right?

Many times we have negative automatic thoughts that influence our mood, these thoughts may not always be entirely correct. When this happens, this is called a cognitive distortion (hand out Appendix T: Cognitive Distortions).

Allow everyone a minute or two to review the cognitive distortions hand-out.

Ask the group: Can you identify any of these that you do?

Allow some time for group discussion here.

Provide Appendix U – Thought Record (part 1) and discuss. Provide at least 1 example for identifying thoughts and related emotions. Allow for group discussion, and allow group members to create their own examples as well.

*[end session 5 here. Homework – use Thought Record (part 1) to identify and record automatic thoughts and cognitive distortions throughout the coming week. Continue to track/log caregiver stress using the caregiver stress checklist]*

*[begin session 6 here]*

Brief review of previous session (identifying automatic thoughts / cognitive distortions]

Check-In Procedure (10-15 minutes) – Discuss level of caregiver stress and highest daily rating; discuss identification of negative automatic thoughts.

### Thought Challenging

When we have a negative thought, the first step to challenging it is to identify if it is a cognitive distortion and if so, what kind of cognitive distortion it is. Next, we can do a few things. One of which is identifying any evidence for and evidence against it. When we do this, it's not uncommon to think of one or two things that fall within the evidence-for column. However, in most cases, we can come up with a lot more evidence against a thought than evidence for it.

Another way to challenge a thought is to imagine what you would say to a friend who told you they're having this thought. Sometimes we can get caught up in ourselves a little bit, so this exercise depersonalizes the thought and allows us to think about it more critically.

A third way is to look at the actual likelihood of a thought. Ask yourself three questions: (1) what's the absolute worst that could happen? (2) What's the absolute best that could happen? (3) What's the most likely scenario? Many times, our negative automatic thought leans closer to the absolute worst scenario, when in all actuality, that thought is quite unlikely to happen.

Pass out Appendix V: Thought Record (part 2) and discuss the example.



Allow for some group discussion here, and allow the group to come up with additional examples for identifying and challenging thoughts.

Give everyone the handout, “20 Questions to Challenge Negative Thoughts” (Appendix W) to review. If there is time, allow for some discussion here.

*[end session 6 here]*

*Homework for the coming week:*

- Continue with the Caregiver Stress Symptom Checklist.
- Practice thought challenging strategies.

**Overall purpose of these sessions:** These sessions are designed to introduce the idea of negative automatic thoughts and cognitive distortions (session 5) and challenging these thoughts and distorted thinking patterns (session 6). Within the cognitive behavioral framework, identifying and modifying negative automatic thoughts and cognitive distortions is a principle mechanism of action to reducing levels of distress and maladaptive thinking patterns which may be fueling psychopathology (Beck, 2011) – in this case, caregiver burden. The modification of maladaptive thinking patterns into more realistic, adaptive patterns of thinking allows patients to approach potentially stress-inducing situations with more accurate appraisals, thus decreasing level of distress (Beck, 2011). When coupled with previous interventions that increase distress tolerance and personal sense of agency, caregivers will be more likely to re-establish a sense of self-identity and personal sense of mastery (Beck, 2011; Dimidjian et al., 2011) within the caregiving context, thus reducing levels of role captivity and caregiver burden.

## APPENDIX P: CBT SESSION SEVEN

Brief review of previous session (negative automatic thoughts and thought challenging)

Check-In Procedure (10-15 minutes) – Discuss level of caregiver stress and highest daily rating; discuss thought challenging home practice.

### Problem Solving with Problem Behaviors

This session should be fairly open for discussion – one person may be experiencing problem behaviors that other members may have experienced and learned how to manage. In these instances, allow the group members to discuss their ways of dealing with problem behaviors.

Start the session by asking group members: does anyone experience any problem behaviors from your care recipient? These can be things like agitation, anger, aggression, wandering, hallucinations, “sundowning,” etc.

Allow for some group discussion here.

What are some ways that you cope or try to deal with some of these problem behaviors?

Allow for some group discussion here.

Let’s talk about some general ways to reduce problem behaviors. A lot of times, being patient and understanding can go a long way. However, this may be difficult at times when we are already at our stress limits. As a result, taking care of yourself and proper stress management through some of the things that we’ve discussed so far is going to help you to not only feel better, but be better equipped to provide care.

If someone is upset, it’s important to listen to why they are upset. Many times, people with dementia can become frustrated because they aren’t able to verbalize or communicate their wants/needs effectively. In these instances, it’s really important to provide a calm, listening ear along with reassurance in order to find out what they may need.

Positive distractions can go a long way. Try to engage the person in a pleasant activity that they enjoy to redirect them away from whatever may have been making them upset.

Modifying the environment can also help with some problem behaviors. An overwhelming environment can lead to overwhelmed feelings; decreasing distractions or removing any specific objects that may be the focus of any anger/aggression; making the environment safe and comfortable for the person.

Pain and other medical conditions can also cause changes in behavioral patterns. If you notice any “spikes” in problem behaviors or overall changes in behavioral patterns, it may be recommended to get a medical check-up to rule out pain or other medical conditions.

For more information on specific problem behaviors, visit: <https://www.alz.org/help-support/caregiving/stages-behaviors>

### Homework for the Coming Week:

- Continue with the Caregiver Stress Symptom Checklist.

- Pick 1:
  - Continue to practice mindfulness for at least 5-10 minutes each day.
  - Continue to practice at least one relaxation strategy each day.
  - Continue to engage in pleasant activities.
  - Continue practice thought challenging strategies.

**Overall purpose of this session:** This session is designed not to be educational, but instead takes a process-oriented approach to provide an open environment in which group members can provide group/peer support, group-based problem-solving, and social support. Given the moderative quality of social support on the effectiveness of group-based interventions (Dadds & McHugh, 1992; Mallinckrodt, 1989; Steketee, 1993; Thrasher et al., 2010; Yalom & Leszcz, 2005), it is important to include this into the treatment model, as it will increase the impact of previous sessions and provide an environment in which like-minded peers can come together in support of one another. When taken into context of previous sessions designed to increase distress tolerance, coping repertoire, mastery, and agency and decrease role captivity, this session should increase these effects and the overall impact of the treatment itself (Mallinckrodt, 1989; Yalom & Leszcz, 2005). It is important to include this session towards the end of the treatment protocol, as previous sessions will have allowed for group-based rapport and group cohesiveness to be built, thus increasing the impact of the interpersonal process environment of this session (Yalom & Leszcz, 2005).

## APPENDIX Q: CBT SESSION EIGHT

Check-In Procedure (10-15 minutes) – Discuss level of caregiver stress and highest daily rating; check-in on encountered problem behaviors based on discussion from session seven.

This session should be predominantly open discussion. Allow group members to reflect on their experiences in group. Some discussion points:

- What have you learned?
- Is there anything you do differently now than before this group started?
- How has your overall stress level been impacted?
- Is there anything that you will continue to do after today?
- Is there anything we didn't cover that you wish we did?
- Is there anything that you wish we had spent more time on?

It is very possible that group members may express some concern, distress, or otherwise ask about no longer being able to engage in therapy after this session. This is a natural response at the end of any therapeutic intervention. Should this question arise in the group, even if only from one single group member, the facilitator(s) should use this as a process-based intervention and turn the question into a group-wide intervention for reflection and processing. The facilitator should lead this process in a way that both normalizes any anxiety for treatment termination while instilling group-wide confidence and hope about moving forward post-termination.

At the end of this session, all participants should complete the satisfaction questionnaire (Appendix X) in order to gauge subjective effectiveness of this intervention and provide individuals with a voice for feedback.

After the group ends, it is possible that some individuals may need further support or care. The Alzheimer's Association's website ([www.alz.org](http://www.alz.org)) has links to online and in-person caregiver support groups, as well as a wealth of information for dementia caregivers. If individuals need individual psychotherapy or counseling, outpatient mental health at EVMS/Sentara can be a referral option as well.

*[Provide all end of treatment assessments to each group member at the end of session eight: CBI, HADS, RCS, SPS, TFI-Coh, WAI-SF, GAS, and STTS-R. If sessions are online, send these assessments to participants immediately following the conclusion of this session – be sure to inform participants that they will be receiving them and to complete them as soon as possible.]*

**Overall purpose of this session:** This session is designed to summarize and reflect on past sessions. Group members will be encouraged to share aspects of the therapy process which they found most helpful (and unhelpful as applicable), reflect on personal growth, and discuss learned strategies from past sessions which can be continually used after treatment cessation. This session falls within the category of termination planning and relapse prevention, which is an important aspect of maintaining treatment gains post treatment cessation (Beck, 2011).

### APPENDIX R: CAREGIVER STRESS SYMPTOM CHECKLIST

As you go throughout the week, check off any of the above symptoms as you experience them:

1. \_\_\_\_\_ Denial --- denial about the disease and its effects.
2. \_\_\_\_\_ Anger --- anger or frustration towards the person with dementia because they aren't able to perform tasks they used to be able to do easily.
3. \_\_\_\_\_ Social Withdrawal --- withdrawing from friends and activities that you used to enjoy.
4. \_\_\_\_\_ Anxiety --- anxiety and worry about the future.
5. \_\_\_\_\_ Depression --- depressed mood that makes it even more difficult to cope with the day-to-day stressors.
6. \_\_\_\_\_ Exhaustion --- the feeling that it is nearly impossible to perform daily tasks because you're too tired or overwhelmed.
7. \_\_\_\_\_ Sleeplessness --- sleep disturbances at night which ultimately makes you more prone to things like exhaustion.
8. \_\_\_\_\_ Irritability --- mood fluctuations that lead to negative responses.
9. \_\_\_\_\_ Difficulty Concentrating --- reductions in your ability to focus on a single given task, or you may have moments of forgetfulness.
10. \_\_\_\_\_ Health Problems --- stress takes a physical toll on you as well, to the point where you may feel physically bad or even fall ill.

On a scale of 1-10 (1 being no stress, 10 being maximum stress), rate your average level of stress each day:

- \_\_\_\_\_ Monday
- \_\_\_\_\_ Tuesday
- \_\_\_\_\_ Wednesday
- \_\_\_\_\_ Thursday
- \_\_\_\_\_ Friday
- \_\_\_\_\_ Saturday
- \_\_\_\_\_ Sunday

**APPENDIX S: PLEASANT ACTIVITIES PLANNING SHEET**

Use the schedule below to plan out pleasant activities for the coming week. Make sure to include things that you can do and enjoy yourself, as well as things you can do with your care recipient if they are able.

Always be sure to balance fun and pleasure with daily responsibilities and duties.

**Pleasant Activity #1:** \_\_\_\_\_

Day/Time I'll do this: \_\_\_\_\_

Possible barriers – what might get in the way? \_\_\_\_\_

How can I plan to work around or avoid these barriers? \_\_\_\_\_

**Pleasant Activity #2:** \_\_\_\_\_

Day/Time I'll do this: \_\_\_\_\_

Possible barriers – what might get in the way? \_\_\_\_\_

How can I plan to work around or avoid these barriers? \_\_\_\_\_

**Pleasant Activity #3:** \_\_\_\_\_

Day/Time I'll do this: \_\_\_\_\_

Possible barriers – what might get in the way? \_\_\_\_\_

How can I plan to work around or avoid these barriers? \_\_\_\_\_

**Pleasant Activity #4:** \_\_\_\_\_

Day/Time I'll do this: \_\_\_\_\_

Possible barriers – what might get in the way? \_\_\_\_\_

How can I plan to work around or avoid these barriers? \_\_\_\_\_

## APPENDIX T: COGNITIVE DISTORTIONS

1. **Mental Filter** → When we notice only what the filter allows or wants us to notice, and we dismiss anything that doesn't "fit."
  - a. Example: only noticing the bad things happening around you while discounting anything good that happens.
2. **All or Nothing Thinking (aka Black and White Thinking)** → Viewing something as either one way or the other – there is no in between.
  - a. Example: "If I'm not perfect, then I have completely failed."
3. **Mind Reading (Jumping to Conclusions)** → Assuming that we know what others are thinking.
  - a. Example: "That person thinks I'm stupid" or "That person thinks I'm a terrible son/daughter"
4. **Emotional Reasoning** → Assuming that because we feel a certain way, the way we think must be true.
  - a. Example: "I feel embarrassed, so I must be a terrible caregiver."
5. **Labeling** → Assigning labels to ourselves or other people.
  - a. Example: "I'm such a useless loser" or "I'm a terrible son/daughter."
6. **Over-Generalizing** → Seeing a pattern based upon a single event, or being overly broad in the conclusions we draw.
  - a. Example: "Everything is always terrible" or "Nothing good ever happens."
7. **Disqualifying the Positives** → Discounting the good things that have happened or that you have done.
  - a. Example: "That doesn't count."
8. **Magnification (Catastrophising) and Minimization** → Blowing things out of proportion (catastrophising) or inappropriately shrinking something to make it seem less important (minimization).
  - a. Example: "This is the worst thing that could happen to me right now" (catastrophising)
  - b. Example: "People are saying I did really well, but I know I made mistakes" (minimizing)
9. **Should / Must Thinking** → Using critical words like 'should,' 'must,' or 'ought' can make us feel guilty or like we have already failed. If we apply 'shoulds' to other people, the result is often frustration.
  - a. Example: "I should have done better" or "I should be able to do this perfectly."
10. **Personalization** → Blaming yourself or taking responsibility for something that wasn't completely your fault. Conversely, this can also be blaming other people for something that was your fault.
  - a. Example: "This was all my fault."
11. **Fortune Telling** → Engaging in thoughts that predict the future, usually in a negative way.
  - a. Example: "The party is going to go terrible" or "Everyone will think I'm an awful person."

## APPENDIX U: THOUGHT RECORD (PART ONE)

Situation	Negative Thought	Emotion
<i>Dad urinated in his pants.</i>	<i>I'm such a terrible son. I'm taking such bad care of my dad.</i>	<i>Sadness, grief, frustration, self-hate.</i>



### APPENDIX V: THOUGHT RECORD (PART TWO)

<b>Situation</b>	<b>Negative Thought</b>	<b>Emotion</b>	<b>Evidence for Thought?</b>	<b>Evidence Against Thought?</b>	<b>New Thought</b>	<b>New Emotion</b>
<i>Dad urinated in his pants.</i>	<i>I'm such a terrible son. I'm taking such bad care of my dad.</i>	<i>Sadness, grief, frustration, self-hate.</i>	<i>I should have been paying closer attention. I should have asked if he needed to go to the bathroom.</i>	<i>This has never happened before. Up until now, the toileting schedule has been fine. Even though he urinated on himself, I still helped clean him up and change his clothes.</i>	<i>Dad urinated on himself, but this is because of his dementia – not because I'm a terrible caregiver. I'm doing the best I can.</i>	<i>Less sad, less grief, less self-hate. Motivated to provide better care and to do my best for my dad.</i>

## **APPENDIX W: 20 QUESTIONS TO CHALLENGE NEGATIVE THOUGHTS**

When faced with negative thoughts, we can ask ourselves the following questions to help us challenge them:

1. Am I confusing a thought for a fact? Would my thought be accepted as correct by other people?
2. Am I jumping to conclusions? Is there actual evidence for this thought?
3. Am I assuming my view of things is the only one possible? Or are there alternative views?
4. Is this thought preventing you from moving forward? Is this thought helping you achieve your goals?
5. What are the advantages and disadvantages of thinking this way?
6. Am I asking questions that have no answers?
7. Am I thinking in all-or-nothing terms? Is there a grey area?
8. Am I using ultimatum words in my thinking?
9. Am I completely condemning myself on the basis of a single event?
10. Am I concentrating on my weaknesses and forgetting my strengths?
11. Am I blaming myself for something that is not really my fault?
12. Am I taking something personally which has little or nothing to do with me?
13. Am I expecting myself to be perfect?
14. Am I using a double standard?
15. Am I paying attention only to one side of things and discounting the other side?
16. Am I overestimating the chances of disaster?
17. Am I exaggerating the importance of a given event?
18. Am I fretting about the way things should be instead of accepting and dealing with them as they are?
19. Am I assuming I can do nothing to change my situation?
20. Am I predicting the future instead of experimenting with it?

Source: Northeastern Ohio Universities Colleges of Medicine and Pharmacy, n.d.

# **APPENDIX X: SATISFACTION WITH THERAPY AND THERAPIST SCALE, REVISED (STTS-R)**

Please select the response that best describes your opinion of your satisfaction with the therapy and therapists in the group CBT treatment attended/completed by you recently. Use the following scale to respond to each item:

1 = Strongly Disagree    2 = Disagree    3 = Neutral    4 = Agree    5 = Strongly Agree

1. \_\_\_\_\_ I am satisfied with the quality of the therapy I received.
2. \_\_\_\_\_ The therapist listened to what I was trying to get across.
3. \_\_\_\_\_ My needs were met by the program.
4. \_\_\_\_\_ The therapist provided an adequate explanation regarding my therapy.
5. \_\_\_\_\_ I would recommend the program to a friend.
6. \_\_\_\_\_ The therapist was not negative or critical towards me.
7. \_\_\_\_\_ I would return to the clinic if I needed help.
8. \_\_\_\_\_ The therapist was friendly and warm towards me.
9. \_\_\_\_\_ I am now able to deal more effectively with my problems.
10. \_\_\_\_\_ I felt free to express myself.
11. \_\_\_\_\_ I was able to focus on what was of real concern to me.
12. \_\_\_\_\_ The therapist seemed to understand what I was thinking and feeling.

Please select the response which you feel most accurately answers the next question:

13. How much did this treatment help with the specific problem that led you to therapy?
  1. Made things a lot worse
  2. Made things somewhat worse
  3. Made no difference
  4. Made things somewhat better
  5. Made things a lot better

Scoring:

Satisfaction with Therapy (ST) scale = sum of all odd items (excluding item 13): \_\_\_\_\_

Satisfaction with Therapist (SWT) scale = sum of all even items: \_\_\_\_\_

Item 13 = patient-rated measure of global improvement: \_\_\_\_\_

Source: Oei & Green, 2008

## **APPENDIX Y: MODIFIED PERCEIVED RESEARCH BURDEN ASSESSMENT (MPRBA)**

The purpose of this form is to help understand your views about participating in this research study. As you read each statement, please circle the response that best describes how you feel about the research study that you just completed. Please use the following scale to respond to each question:

1 = Strongly Disagree    2 = Disagree    3 = Neutral    4 = Agree    5 = Strongly Agree

1. \_\_\_\_\_ I felt that this study's visits/sessions were too frequent.
2. \_\_\_\_\_ I felt that this study's visits/sessions lasted too long.
3. \_\_\_\_\_ I felt that participating in this study took too much time away from my friends and family.
4. \_\_\_\_\_ I felt that the researchers asked too many questions, or that the questionnaires were too much.
5. \_\_\_\_\_ I felt that the researchers asked me questions that were too personal.
6. \_\_\_\_\_ I felt that the researchers called or contacted me or my family members too often.
7. \_\_\_\_\_ I felt that my personal information was not kept private.
8. \_\_\_\_\_ I felt that the research site was too far away.
9. \_\_\_\_\_ I felt that it was inconvenient to get to the research location.
10. \_\_\_\_\_ I felt that it was inconvenient to park at the research location.
11. \_\_\_\_\_ I felt that I became emotionally upset by the research procedures / sessions.
12. \_\_\_\_\_ At some point during this study, I had second thoughts about my decision to participate.
13. \_\_\_\_\_ At some point during this study, I regretted my decision to participate.
14. \_\_\_\_\_ I felt that this study took too much time away from my chores and household responsibilities.
15. \_\_\_\_\_ I felt that this study took too much time away from my or my family member's job(s).
16. \_\_\_\_\_ I felt that it costed too much to transport myself or get to the research location.

Scoring:

- Psychological burden subscale = sum of items 4, 5, 6, 7, 11, 13, & 14 \_\_\_\_\_
- Logistical burden subscale = sum of items 1, 2, 3, 8, 9, 10, 15, 16, & 17 \_\_\_\_\_
- Physical burden subscale = item 12 \_\_\_\_\_
- Total burden scale = sum of subscales \_\_\_\_\_

Adapted from Lingler, et al 2014

## VITA

### EDUCATION

- 2016 – Present**      **Virginia Consortium Program in Clinical Psychology**  
Ph.D., Clinical Psychology, expected August 2022
- 2016 – 2018**      **Old Dominion University**  
M.S., Experimental Psychology  
*Thesis: Testing the Efficacy of Transcranial Magnetic Stimulation (TMS) in Treating Depression in Patients with Cognitive Impairment*
- 2012 – 2014**      **Barton College**  
B.S., Psychology

### CLINICAL EXPERIENCE

- 2020 – Present**      **Washington State University, Counseling and Psychological Services**  
Pre-Doctoral Psychology Intern

### SELECT PUBLICATIONS & PRESENTATIONS

**Schaffer, D.**, Okhravi, H., & Neumann, S. (2021). Low-frequency transcranial magnetic stimulation (LF-TMS) in treating depression in patients with impaired cognitive functioning. *Archives of Clinical Neuropsychology*, 36, 801-814.

Debb, S., **Schaffer, D.**, & Colson, D. (2020). A reverse digital divide: comparing information security behaviors of Generation Y and Generation Z adults. *International Journal of Cybersecurity Intelligence & Cybercrime*, 3, 42-55.

**Schaffer, D.** & Debb, S. (2020). Assessing Instagram use across cultures – a confirmatory factor analysis. *Cyberpsychology, Behavior, & Social Networking*, 23, 100-106.

**Schaffer, D.** & Debb, S. (2019). Validation of the Online Security Behaviors and Beliefs Questionnaire with college students in the United States. *Cyberpsychology, Behavior, & Social Networking*, 22, 766-770.

**Schaffer, D.** & Debb, S. (2019, October). *Assessing Instagram use across cultures – a confirmatory factor analysis*. Symposium paper talk for the Annual APA Technology, Mind, & Society Division Conference, Washington, DC.

**Schaffer, D.** & Debb, S. (June, 2019). *Assessing Instagram use across cultures – a confirmatory factor analysis*. Symposium paper talk for the 24<sup>th</sup> Annual CyberPsychology, CyberTherapy, & Social Networking Conference, Norfolk, VA.

**Schaffer, D.**, Nason, S., & Neumann, S. (2018, April). *Examining the treatment efficacy of Transcranial Magnetic Stimulation (TMS) in improving sleep quality among patients with major depressive disorder (MDD)*. Poster presented at the 39<sup>th</sup> Society for Behavioral Medicine Conference, New Orleans, LA.