

COPING WITH DEMENTIA: A RESOURCE FOR FAMILIES AND LOVED ONES

A Dissertation

Submitted to the Faculty of Immaculata University

by

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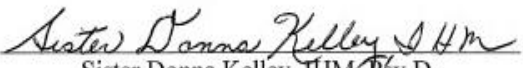
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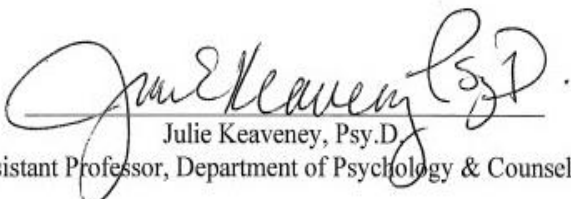
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Margaret Czapski

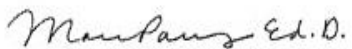
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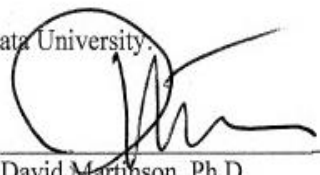
  
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## DISSERTATION ABSTRACT

### COPING WITH DEMENTIA: A RESOURCE FOR FAMILIES AND LOVED ONES

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M.A., Immaculata University, 2021

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Directed by Sister Donna Kelley, IHM, Psy.D.

Dementia is a neurodegenerative disease currently affecting millions of people and their families around the world. Witnessing the gradual loss of a loved one to dementia and providing informal care is a challenging experience, and more resources are needed to help families manage the impact of dementia. A literature review was conducted to explore the effects of having a loved one with dementia, as well as effective Cognitive Behavioral Therapy (CBT) intervention strategies to improve well-being and coping abilities in this population. Findings demonstrated that family caregiving of dementia can lead to psychiatric distress and physical health problems. Furthermore, grief is present throughout the various stages of the disease and is characterized by ambiguity and uncertainty. CBT interventions are effective in reducing psychological distress in families, specifically with thought modification strategies and behavioral adaptation skills. CBT techniques help families move through the complicated grief process by encouraging acceptance of loss, recognition of distressing emotions, and adjustment to change. The findings of this review were integrated to create a CBT-based self-help manual, which included psychoeducation, coping skills, and resources. This research

highlights the need for health professionals to address family caregivers' well-being, as well as demonstrates the importance of providing accessible resources to support families throughout the course of the disease.

*Keywords:* dementia, family members, caregivers, cognitive behavioral therapy (CBT), coping skills, grief, ambiguous loss, geriatric care, aging, self-help manual

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## Table of Contents

|                                      |     |
|--------------------------------------|-----|
| Title Page                           |     |
| Certificate of Dissertation Approval |     |
| Copyright .....                      | iii |
| Abstract .....                       | iv  |
| Acknowledgements.....                | vi  |
| Table of Contents .....              | vii |
| List of Tables and Figures.....      | xi  |
| Chapter I                            |     |
| Introduction.....                    | 1   |
| Statement of the Problem.....        | 3   |
| Statement of the Purpose .....       | 4   |
| Chapter II                           |     |
| Literature Review.....               | 5   |
| Overview of Dementia.....            | 5   |
| Types of Dementia.....               | 6   |
| Alzheimer’s Disease .....            | 7   |
| Vascular Dementia.....               | 9   |
| Frontotemporal Dementia .....        | 10  |
| Dementia with Lewy Bodies.....       | 11  |
| Other Dementia Types .....           | 12  |
| Impact of Dementia on Families.....  | 15  |
| Caregiving.....                      | 16  |

|   |    |
|---|----|
| Financial Impacts .....   | 17 |
| Physical Health Impacts.....                                      | 18 |
| Psychological Impacts .....                                       | 21 |
| Protective Factors.....   | 26 |
| Family Relationships and Roles.....                               | 28 |
| Grief and Loss.....   | 33 |
| <br>Chapter III   |    |
| Advanced Literature Review .....                                  | 37 |
| Overview of Cognitive Behavioral Therapy (CBT) .....              | 37 |
| CBT and Diversity .....   | 38 |
| CBT Interventions for Families of Individuals with Dementia ..... | 39 |
| Efficacy of CBT Techniques .....                                  | 42 |
| Efficacy of a Telephone-Based CBT Intervention.....               | 47 |
| Efficacy of a Computerized CBT Intervention .....                 | 49 |
| Diversity Considerations.....                                     | 51 |
| CBT Interventions for Grief and Loss .....                        | 53 |
| Applying CBT to the Dementia Grief Model .....                    | 57 |
| Conclusion .....  | 59 |
| <br>Chapter IV  |    |
| Discussion.....   | 61 |
| Introduction.....   | 61 |
| A Proposed Self-Help Manual for Coping with Dementia.....         | 61 |
| Psychoeducation .....   | 63 |



|  |     |
|--|-----|
| Chapter 1: What is Dementia? .....                 | 64  |
| Chapter 2: All About Family Caregiving.....        | 64  |
| Chapter 3: The Unique Grief Process .....          | 64  |
| Chapter 4: What is CBT? .....                      | 65  |
| Thought Modification .....                         | 66  |
| Chapter 5: Recognizing Your Thoughts .....         | 66  |
| Emotional Processing.....                          | 71  |
| Chapter 6: Understanding Your Feelings .....       | 71  |
| Behavioral Activation and Stress Management .....  | 74  |
| Chapter 7: Improving Your Behaviors .....          | 74  |
| Additional Resources .....                         | 76  |
| Chapter 8: Additional Resources .....              | 76  |
| Clinical Implications .....                        | 76  |
| Limitations of the Study.....                      | 77  |
| Future Directions .....                            | 77  |
| References.....                                    | 79  |
| Appendix A: The Dementia Grief Model .....         | 93  |
| Appendix B: Unhelpful Thoughts in Caregivers ..... | 96  |
| Appendix C: Behavioral Activation Steps .....      | 99  |
| Appendix D: Respite Care .....                     | 103 |
| Appendix E: Relaxation Techniques .....            | 106 |
| Appendix F: Managing Challenging Behaviors .....   | 109 |
| Appendix G: Additional Resources .....             | 113 |

Appendix H: RERB Approval Form.....117

## List of Tables and Figures

|   |     |
|---|-----|
| Table 1: Table of Contents.....                                   | 62  |
| Table 2: Common Unhelpful Thinking Styles.....                    | 67  |
| Table 3: Modifying Negative Thoughts.....                         | 69  |
| Table 4: Common Emotions for Families Dealing with Dementia ..... | 72  |
| Figure C1: Behavioral Activation Schedule .....                   | 101 |

## **Chapter I**

### **Introduction**

Geriatric care is a critical area in the fields of psychology and medicine, and it is especially significant as the older adult population continues to increase (Harada et al., 2013). More specifically, the number of Americans over the age of 65 is expected to double from 52 million in 2018 to 95 million by 2060 (Mather et al., 2019). This increase in the older adult population is attributed to the baby boom generation born between 1946 and 1964 (Alzheimer's Association, 2021a; Mather et al., 2019). Furthermore, reduced mortality rates in older age have caused the average life expectancy in the United States to increase to 78.6 years as of 2017 (Mather et al., 2019). Therefore, to understand this expanding population, research on the aging process is vital—especially given changes that may occur in the brain. While every individual will experience brain changes as they age (Harada et al., 2013), some older adults will develop pathological alterations that will interfere with their ability to function, known as dementia. Research shows that 11.3%, or more than one in nine, adults over 65 have Alzheimer's disease, which is the most common type of dementia (Alzheimer's Association, 2021a). Therefore, to inform proper diagnosis and intervention, it is important to understand the differences between normal and pathological aging.

Normal structural changes in the brain that occur as people age include: (1) a reduction in grey matter, the part of the brain that contains the neuronal cell bodies, particularly in the prefrontal cortex and temporal lobes, and (2) a decrease in white matter, found in the deeper tissues of the brain (Harada et al., 2013). Consequently, mild cognitive changes occur in normal aging including gradual declines in processing speed,

complex attention, abstract thought, mental flexibility, and response inhibition (Harada et al., 2013). It also is typical for working memory, the ability to encode new information, and declarative memory, memory for facts or events, to decline (Harada et al., 2013). However, the ability to retain information that has been learned, visuospatial abilities like object and spatial perception and recognition of familiar objects, and overall language ability remain intact in normal aging (Harada et al., 2013). While cognitive changes occur in the typical aging process, they do not usually impair the individual's ability to perform daily activities (Harada et al., 2013). In contrast, the cognitive shifts that take place in dementia are more pervasive and interfere with an individual's ability to carry out daily functions and care for themselves (American Psychiatric Association, 2022; Harada et al., 2013).

Because individuals with dementia need support to carry out daily tasks, family members are often involved in the caregiving process. In fact, a majority of individuals with dementia do not live in nursing homes or other care facilities, resulting in millions of Americans providing informal care to their loved ones with dementia (Alzheimer's Association, 2021a; Mather & Scommegna, 2020). Research suggests that caring for individuals with dementia is a physically and psychologically taxing endeavor due to the difficult functional changes that occur and the need for constant supervision (Alzheimer's Association, 2021a; Mather & Scommegna, 2020). Furthermore, loved ones often witness personality and behavioral changes in the individual, and they experience shifts in family dynamics and relationships. There is also growing research on the unique grief process that occurs for loved ones of dementia patients, due to the ambiguity of the individual being physically present but cognitively and emotionally absent (Benbow et al., 2019;

Blandin & Pepin, 2017; Boss, 2010; Boss & Yeats, 2014; Chirico et al., 2021; Van Wijngaarden et al., 2018; Youell et al., 2016). Therefore, it is important to raise awareness about the secondary psychological impact that occurs when a family member has dementia, and to make available supportive resources to help reduce the negative impacts of mental and physical illness that might arise from this disease process. This research examined the effects of dementia on family members and explored interventions to assist this population in managing the difficulties associated with caring for a family member with dementia.

### **Statement of the Problem**

Dementia is a deadly disease that continues to become more prevalent as the population ages (Alzheimer's Association, 2021a; Mather et al., 2019; World Health Organization, 2021). Many dementia patients are living at home and in the community among family members and loved ones (Alzheimer's Association, 2021a; Mather & Scommegna, 2020). Therefore, many individuals are providing some aspect of dementia care or are directly witnessing the course of this disease in someone close to them (Alzheimer's Association, 2021a; Mather & Scommegna, 2020). Dementia is not only detrimental to the individual; the impacts of dementia are pervasive and extend to those around them. The neurodegenerative process is distressing to family members and loved ones due to the significant cognitive, behavioral, and personality changes that occur to the individual, which are difficult to manage (Alzheimer's Association, 2021a; Chirico et al., 2021; Grafstrom & Winblad, 1995; Mather & Scommegna, 2020; Ory et al., 1999; Ory et al., 2000; Schulz et al., 1995; Schulz & Sherwood, 2008; Svanberg et al., 2011). There is consistent research on the physical and psychological effects of caregiving for a

dementia patient, but there is less research on how dementia impacts loved ones outside of the caregiving role. In addition, while there is research on the effectiveness of therapeutic interventions for family caregivers, more interventions are needed for families to apply and utilize consistently in their everyday lives, such as educational resources and self-help manuals, to improve their ability to manage the impact of dementia. More specifically, families need resources that provide evidence-based therapeutic strategies to cope with the unique grief process and the experience of ambiguous loss associated with dementia.

### **Statement of the Purpose**

The purpose of this research was to utilize the literature to determine the effects of having a family member with dementia and its impact on loved ones' well-being. Furthermore, the literature was used to identify effective intervention strategies to address these psychological effects, particularly from a Cognitive Behavioral Therapy (CBT) orientation. These findings were compiled to construct a self-help resource manual for family members of individuals with dementia to aid in managing their experiences of caring for and witnessing the devastating effects of dementia on their loved one.

## Chapter II

### Literature Review

#### Overview of Dementia

There are currently more than 55 million people living with dementia worldwide, with nearly 10 million new cases each year (World Health Organization, 2021). Dementia is presently the seventh leading cause of death, and 65% of dementia deaths occur in women (World Health Organization, 2021). Researchers and practitioners have identified the physiological, behavioral, and psychological presentation of this deadly disease. Dementia is a syndrome characterized by a deterioration in cognitive functioning that exceeds the typical decline of normal, biological aging (World Health Organization, 2021). Dementia results in structural and chemical brain changes, which lead to a loss of neurons and shrinkage of brain volume (Denning & Sandilyan, 2015). It can affect various cognitive domains, including memory and learning, language, executive functioning, perceptual-motor, complex attention, and social cognition skills (American Psychiatric Association, 2022; World Health Organization, 2021). Additionally, cognitive impairment is often accompanied by psychological and behavior changes, such as increased aggression and apathy, lack of empathy, reduced inhibition, wandering, hallucinations, and changes in sleep and eating patterns (American Psychiatric Association, 2022; Perrotta, 2020; World Health Organization, 2021). Age is the strongest known risk factor for dementia (World Health Organization, 2021). However, young onset dementia, which occurs when symptoms present prior to age 65, accounts for 9% of dementia cases (World Health Organization, 2021). Other possible risk factors for dementia include depression, social isolation, low educational attainment, cognitive



inactivity, air pollution, and health issues such as alcohol use, obesity, high blood pressure and cholesterol, smoking, and lack of exercise (World Health Organization, 2021). Research also suggests that dementia can be a result of various diseases that affect the brain, either primarily or secondarily (World Health Organization, 2021). Several instruments are used to diagnose dementia including magnetic resonance imaging (MRI), positron emission tomography (PET) scans, clinical interviews, and neuropsychological test administration (Perrotta, 2020). *The Diagnostic and Statistical Manual of Mental Disorders* (5th ed., text rev.; *DSM-5-TR*; American Psychiatric Association, 2022) identifies and describes criteria for several types of dementia based on various etiologies.

### **Types of Dementia**

The *DSM-5-TR* classifies cognitive impairment as either a major or mild neurocognitive disorder (American Psychiatric Association, 2022). The criterion for neurocognitive disorder includes evidence of significant cognitive decline in one or more cognitive domains from a previous level of performance (e.g., language, memory, visuospatial skills). A neurocognitive disorder is classified as “major” if the cognitive deficits interfere with the individual’s independence in everyday activities, including complex instrumental activities of daily living such as paying bills and managing medication. When cognitive deficits do not impact the individual’s daily functioning, the individual is diagnosed with a mild neurocognitive disorder. Additionally, to meet criteria for a neurocognitive disorder, the cognitive deficits must not occur exclusively in the context of a delirium, and they cannot be better explained by another mental disorder such as depression or schizophrenia (American Psychiatric Association, 2022).

Depending on the area of the brain initially and primarily impacted, dementia is classified as either cortical or subcortical (Perrotta, 2020; Shaik & Varma, 2012). Cortical dementias impact the structure of the cerebral cortex, or the outermost layer of the brain, which is responsible for higher level cognitive processes. Therefore, cortical dementias are characterized by severe loss of brain cells and early changes in memory, language, and abstract thought (Perrotta, 2020). The most common cortical dementias are Alzheimer's disease and frontotemporal dementia (Shaik & Varma, 2012). On the other hand, subcortical dementias impact structures below the cerebral cortex, such as the basal ganglia, thalamus, and white matter (Perrotta, 2020; Shaik & Varma, 2012). Subcortical dementias are characterized by a decline in motor speed and coordination, decreased attention, and changes in personality and emotions, with visuospatial and language deficits being less likely (Perrotta, 2020; Shaik & Varma, 2012). The most common subcortical dementias are vascular dementia, progressive supranuclear palsy, Parkinson's disease, and Huntington's disease (Perrotta, 2020; Shaik & Varma, 2012). Shaik and Varma (2012) also identified a category of cortico-subcortical dementias characterized by a combination of cortical and subcortical deficits, including dementia with Lewy bodies and the rare Creutzfeldt-Jakob disease. The clinical characteristics of each of the cortical and subcortical dementias are described in the following sections.

### ***Alzheimer's Disease***

Alzheimer's disease is the most common type of dementia, accounting for at least 60% of all dementia cases (American Psychiatric Association, 2022; World Health Organization, 2021). It is characterized by the presence of amyloid plaques and neurofibrillary tangles in the brain, as well as an acetylcholine deficiency, which is a

neurotransmitter involved in learning and memory (Denning & Sandilyan, 2015; Perrotta, 2020). There is also evidence of a genetic mutation in the diagnosis of early onset Alzheimer's disease (American Psychiatric Association, 2022). The diagnostic criteria for Alzheimer's dementia include evidence of decline in memory and learning and at least one other cognitive domain (e.g., language, visuospatial skills, executive functioning), as well as a lack of evidence of mixed etiology (American Psychiatric Association, 2022). In major neurocognitive disorder due to Alzheimer's disease, there are commonly deficits in language (e.g., difficulties understanding or producing speech) and visuoconstructional skills (e.g., difficulties with perceptual-motor abilities and visuospatial tasks), as well as memory decline (American Psychiatric Association, 2022). The typical onset of Alzheimer's disease is between the ages of 80 and 90, with early onset occurring between the ages of 50 and 60 (American Psychiatric Association, 2022). Alzheimer's disease presents with insidious onset (subtle changes and minimal impairment) and gradual progression (symptoms slowly get worse over time; American Psychiatric Association, 2022). The early stages of Alzheimer's are marked by memory loss of recent events, inability to learn new information, and word-finding difficulties (Denning & Sandilyan, 2015; Perrotta, 2020; Shaik & Varma, 2012). As the disease progresses, short-term memory, long-term memory, and the ability to understand or express speech continue to decline, leading to impairment in everyday activities (Denning & Sandilyan, 2015; Perrotta, 2020). Individuals with Alzheimer's disease also experience impairments in visuospatial skills, resulting in disorientation and difficulty navigating unfamiliar, and eventually, familiar places (Perrotta, 2020; Shaik & Varma, 2012). In later stages, these visuospatial deficits may lead to failure to recognize familiar faces

(Shaik & Varma, 2012). In addition to cognitive impairments, 80% of individuals with Alzheimer's disease display behavioral and psychological changes (American Psychiatric Association, 2022). At the mild level, these symptoms include depression and apathy (American Psychiatric Association, 2022; Perrotta, 2020). At the severe level, individuals with Alzheimer's disease can experience psychotic features, agitation, and wandering (American Psychiatric Association, 2022). By the late stages of this disease, individuals become completely dependent on others to carry out activities of daily living and the time from diagnosis to death ranges from 3 to 10 years (American Psychiatric Association, 2022; Perrotta, 2020).

### ***Vascular Dementia***

The second most common type of dementia is vascular dementia, which is a subcortical type of dementia (American Psychiatric Association, 2022; Perrotta, 2020; Shaik & Varma, 2012). The diagnostic criteria for vascular dementia are an onset of cognitive deficits related to a cerebrovascular event, the presence of cerebrovascular disease, and a decline in complex attention and executive function (American Psychiatric Association, 2022). Vascular risk factors include hypertension, hyperlipidemia, diabetes, smoking, poor diet, and obesity (Dening & Sandilyan, 2015). These conditions or patterns lead to reduced blood supply to the brain, which impacts the functioning of neurons and eventually leads to the death of brain cells (Dening & Sandilyan, 2015). Vascular dementia may develop acutely after a stroke, but usually presents as a gradual progression (Dening & Sandilyan, 2015). Symptoms vary based on the nature and location of the brain damage, and can also include memory and language difficulties, slowed cognitive processing, depression, anxiety, and apathy in addition to attention and

executive functioning deficits (Denning & Sandilyan, 2015). The average life expectancy for vascular dementia is lower than Alzheimer's disease at approximately 5 years following diagnosis (Alzheimer's Society, 2021). This is attributed to the likelihood of dying from a stroke or heart attack due to underlying cerebrovascular risk factors.

### ***Frontotemporal Dementia***

Another type of cortical dementia is frontotemporal dementia, an umbrella term that includes a range of conditions depending on which part of the frontal or temporal lobe is affected (Denning & Sandilyan, 2015; Shaik & Varma, 2012). Frontotemporal dementia is marked by severe atrophy in the frontal and/or temporal lobes, and there is evidence of a genetic mutation in the etiology of some cases of frontotemporal dementia (American Psychiatric Association, 2022; Shaik & Varma, 2012). Like Alzheimer's disease, frontotemporal dementia presents with insidious onset and gradual progression (American Psychiatric Association, 2022). However, frontotemporal dementia has an earlier onset and a faster decline than late onset Alzheimer's disease (American Psychiatric Association, 2022). Frontotemporal dementia also differs from Alzheimer's disease in that memory, learning, and perceptual-motor functioning are relatively spared (American Psychiatric Association, 2022; Shaik & Varma, 2012). One type of frontotemporal dementia is the behavioral variant, which is characterized by personality and behavior changes, such as disinhibition, loss of insight, apathy, lack of empathy and judgment, inflexibility, impulsivity, perseverative or compulsive behavior, hyperorality, and dietary changes (American Psychiatric Association, 2022; Denning & Sandilyan, 2015; Perrotta, 2020; Shaik & Varma, 2012). There is also a decline in social cognition and executive abilities (American Psychiatric Association, 2022; Shaik & Varma, 2012).

More specifically, assessment results demonstrate difficulties with organization, set shifting, perseveration, and attention (Shaik & Varma, 2012). A second form of frontotemporal dementia is the language variant, which is marked by a decline in language ability such as speech production, word finding, object naming, grammar, or word comprehension (American Psychiatric Association, 2022). Individuals with semantic dementia lose the meaning of words and objects, while individuals with primary progressive aphasia have difficulty producing speech (Denning & Sandilyan, 2015; Shaik & Varma, 2012). The prognosis for frontotemporal dementia is approximately 6–8 years, depending on the specific form (Perrotta, 2020).

### ***Dementia with Lewy Bodies***

Dementia with Lewy bodies features an earlier onset than Alzheimer's disease and later onset than frontotemporal dementia, with symptoms typically emerging between 70 and 80 years of age (American Psychiatric Association, 2022; Perrotta, 2020). It is characterized by the presence of Lewy bodies, or clusters of alpha-synuclein protein in cells, in the cerebral cortex (Denning & Sandilyan, 2015). A core feature of dementia with Lewy bodies is parkinsonism that occurs at least one year after the onset of cognitive decline, which can include physical rigidity and slowness, shuffled gait, reduced facial expression, and less frequently, tremor (American Psychiatric Association, 2022; Denning & Sandilyan, 2015; Shaik & Varma, 2012). These motor symptoms often lead to recurrent falls (American Psychiatric Association, 2022; Denning & Sandilyan, 2015). Other core features of dementia with Lewy bodies include fluctuating attention and alertness, and well-formed visual hallucinations, such as perceiving items in the room as moving or seeing objects or people that are not actually present (American Psychiatric

Association, 2022; Dening & Sandilyan, 2015; Shaik & Varma, 2012; Teeple et al., 2009). Other common symptoms that are present in individuals with this type of dementia include rapid eye movement (REM) sleep behavior disorder and neuroleptic sensitivity (American Psychiatric Association, 2022). In contrast to Alzheimer's disease, dementia with Lewy bodies presents with early changes in complex attention and executive function, rather than learning and memory (American Psychiatric Association, 2022). More specifically, this may present as disorientation to space, difficulty planning, and fluctuations in awareness (Dening & Sandilyan, 2015). However, individuals with dementia with Lewy bodies may also present with memory decline, confusion, and speech difficulties (Shaik & Varma, 2012). The combination of motor and autonomic deficits often leads to increased impairment in everyday functioning, likely resulting in a lower quality of life than Alzheimer's disease (American Psychiatric Association, 2022). The prognosis for dementia with Lewy bodies is approximately five to seven years (American Psychiatric Association, 2022).

### ***Other Dementia Types***

The *DSM-5-TR* identifies various diseases and conditions that can lead to dementia. First, Parkinson's disease is a neurodegenerative disease that involves the death of cells that produce dopamine, as well as an accumulation of the alpha-synuclein protein like dementia with Lewy bodies (Perrotta, 2020). However, in contrast to dementia with Lewy bodies, motor symptoms and an established Parkinson's disease must precede cognitive decline by at least one year to meet diagnostic criteria for a neurocognitive disorder due to Parkinson's disease (American Psychiatric Association, 2022). In addition to cognitive decline, individuals with Parkinson's dementia may

experience apathy, depressed or anxious mood, hallucinations or delusions, personality changes, and REM sleep behavior disorder (American Psychiatric Association, 2022).

This type of dementia is more common in males and symptoms are usually expressed when an individual is in their early 60s (American Psychiatric Association, 2022).

Additionally, approximately 75% of individuals diagnosed with Parkinson's disease will develop a major neurocognitive disorder, while 27% will develop a mild neurocognitive disorder (American Psychiatric Association, 2022). The prognosis of Parkinson's disease is five to fifteen years, depending on the age of onset (Perrotta, 2020).

Another type of neurodegenerative disease that leads to dementia is Huntington's disease, which is an autosomal dominant genetic disease caused by a repeated molecule on the HTT gene on chromosome 4 (American Psychiatric Association, 2022). Onset typically occurs in middle age, with an average age of diagnosis of 40-years-old (American Psychiatric Association, 2022; Denning & Sandilyan, 2015; Perrotta, 2020). Huntington's disease presents with early cognitive changes in executive functioning (American Psychiatric Association, 2022), as well as subtle behavioral changes such as depression, anxiety, apathy, obsessive-compulsive symptoms, and irritability (American Psychiatric Association, 2022; Perrotta, 2020). Motor symptoms then develop, including motor slowing and involuntary choreiform, dancelike movements that progress to impairments in speech, postural stability, and swallowing in the later stages of the disease (American Psychiatric Association, 2022). After motor symptoms are diagnosed, the approximate time to death is 15 years (American Psychiatric Association, 2022).

Substances or medications, including alcohol, inhalants, and sedative, hypnotic, and anxiolytic substances may also cause dementia (American Psychiatric Association,



2022). This occurs when cognitive impairments persist past the usual duration of intoxication or acute withdrawal, and the course of symptoms is consistent with the timing of use and abstinence (American Psychiatric Association, 2022). The cognitive deficits may be stable or improve after an extended period of abstinence (American Psychiatric Association, 2022). There are usually impairments in executive functioning and memory skills in this type of dementia, and in severe forms there may be motor symptoms and emotional control issues (American Psychiatric Association, 2022). Substance or medication induced neurocognitive disorders are more likely to be severe and persistent if the individual abuses the substance after age 50 due to increased brain changes and reduced plasticity with age (American Psychiatric Association, 2022).

Another type of dementia is related to human immunodeficiency virus (HIV) infection. Approximately 25% of individuals who contract HIV develop a mild neurocognitive disorder and less than 5% develop a major neurocognitive disorder (American Psychiatric Association, 2022). Dementia due to HIV typically presents with subcortical characteristics including impairments in executive functioning, processing speed, attention, and learning (American Psychiatric Association, 2022). In more severe forms, individuals may develop motor and psychiatric symptoms (American Psychiatric Association, 2022). This type of dementia usually presents with a fluctuating course, and it can impact various brain areas resulting in a variety of cognitive patterns (American Psychiatric Association, 2022).

Prion diseases, a group of conditions caused by infectious abnormal proteins in the brain, also cause dementia (American Psychiatric Association, 2022). Prion diseases are known as spongiform encephalopathies and include Creutzfeldt-Jakob disease, variant

Creutzfeldt-Jakob disease, kuru, Gerstmann-Straussler-Scheinker syndrome, and fatal insomnia (American Psychiatric Association, 2022). This type of dementia is characterized by rapid progression and short duration survival rate, as well as abnormal movements and psychiatric symptoms (American Psychiatric Association, 2022). The most common type of prion disease is Creutzfeldt-Jakob disease (CJD), but even this type is rare with one or two cases per one million people (American Psychiatric Association, 2022). Typically, a biomarker of a prion disease is needed when making this diagnosis (American Psychiatric Association, 2022).

In addition, several other medical conditions may contribute to the development of neurocognitive disorders or dementia. These conditions include: (a) lesions, such as tumors, subdural hematoma, or hydrocephalus, (b) hypoxia, (c) endocrine conditions, (d) nutritional conditions, (e) infectious conditions, (f) immune disorders, (g) metabolic conditions, and (h) neurological conditions, such as epilepsy and multiple sclerosis (American Psychiatric Association, 2022). These types of dementia are diagnosed through physical and laboratory examinations that confirm the relationship between a medical condition and the development of neurocognitive deficits. In addition to the negative physical and behavioral effects that dementia has on the individual, this disease also impacts family members and loved ones in various ways.

### **Impact of Dementia on Families**

Currently, more than 11 million Americans provide unpaid care for individuals with dementia (Alzheimer's Association, 2021a), and these individuals tend to be female spouses and adult children of those with dementia (Grafstrom & Winblad, 1995; Schulz & Martire, 2004). Families are likely to be involved in the care of dementia patients due

to the large proportion of individuals with dementia who are living at home. For example, in 2015, 85% of Americans with dementia lived at home or in a supportive care setting, with 80% of these individuals living in traditional community settings (Mather & Scommegna, 2020). This suggests only 15% of Americans with dementia live in nursing facilities (Mather & Scommegna, 2020). However, even when individuals with dementia are residing in residential care settings, 80% had at least one family member assisting with their care (Mather & Scommegna, 2020). Furthermore, studies show that 92% of older adults with dementia receive help from family members or other informal providers (Alzheimer's Association, 2021a). Due to increased life expectancy and chronic diseases, changes to insurance, and advances in technology, the number of caregivers, duration of caregiving, and types of caregiving tasks have changed (Schulz & Martire, 2004).

Caregiving has become more common, can last many years, and involve complex tasks usually performed by paid professionals (Schulz & Martire, 2004). Families who are caring for an individual with dementia suffer financially, physically, and psychologically.

### ***Caregiving***

Schulz and Martire (2004) assert that there is no standard definition of caregivers and explain family caregiving involves providing a high amount of care that goes beyond what is normal in family relationships. The Alzheimer's Association (2021a) identified several common tasks for individuals who care for those with dementia, including instrumental activities of daily living (e.g., preparing meals, shopping, and managing finances), helping with medications, assisting with adherence to treatment recommendations, aiding in activities of daily living (e.g., bathing, dressing, and feeding), managing behavioral symptoms, finding support services, arranging for paid

care, addressing family issues, and providing emotional support. This suggests family members are heavily involved in the informal care of individuals with dementia and make substantial contributions to the caregiving process.

**Financial Impacts.** Studies show that dementia is the most time-intensive and costly type of elder care (Mather & Scommegna, 2020). In 2019, the global societal cost of dementia was estimated as \$1.3 trillion, with 50% attributed to informal care (World Health Organization, 2021). Families of dementia patients endure financial hardships often attributed to decreased employment due to the substantial time dedicated to supervising and assisting with household activities and personal care, services not usually covered by insurance (Alzheimer's Association, 2021a; Mather & Scommegna, 2020; Ory et al., 1999). Furthermore, research indicates that family caregivers with financial difficulties also report higher depressive symptoms (Nam, 2016). There have been attempts, however, by the government to alleviate financial strain occurring from informal caregiving. In March 2021, a bipartisan bill was introduced in Congress titled the Alzheimer's Caregiving Support Act, which would supply grants to provide reimbursement for services such as education and support groups for informal caregivers (Alzheimer's Association, 2021b). Furthermore, in 2021, the Pennsylvania governor signed the Caregiver Support Act to allow more individuals to utilize the Pennsylvania Caregiver Support Program (Commonwealth of Pennsylvania, 2022). This program provides families with financial reimbursement for caregiving costs, resources such as education and support, and access to respite care (Commonwealth of Pennsylvania, 2022).

**Physical Health Impacts.** Caring for an individual with dementia also impacts the physical health of family members (Alzheimer's Association, 2021a; Chiu et al., 2014; Fonareva & Oken, 2014; Ory et al., 1999; Pinguart & Sorensen, 2007; Schulz & Sherwood, 2008; Vitaliano et al., 2003). Increased stress may lead caregivers to be more susceptible to disease and contribute to new or exacerbated health problems (Alzheimer's Association, 2021a; Fonareva & Oken, 2014; Schulz & Martire, 2004; Schulz & Sherwood, 2008). Schulz and Martire (2004) hypothesized that physical health problems may be attributed to the physical demands and psychological distress of caregiving, as well as inherent susceptibilities to illnesses in adult caregivers. Ory et al. (2000) conducted a review of the literature on the health effects of dementia caregiving and found that many studies consistently showed that caregivers are more likely to perceive their overall health as poorer than non-caregivers. In addition, in a meta-analysis of 23 studies comparing health outcomes between dementia caregivers and non-caregivers, Vitaliano et al. (2003) found that dementia caregivers reported more health problems than non-caregivers. Furthermore, dementia caregivers had a higher level of stress hormones and a lower level of antibody responses, suggesting that dementia caregivers have a higher risk of illness. Fonareva and Oken (2014) conducted a more recent review of the physical impact of dementia caregiving and assessed differences between caregivers and non-caregivers in 37 studies that used objective health measures. Results indicated that caregivers had higher sympathetic nervous system activity, changes to metabolism biomarkers, higher risk of cardiovascular disease, heightened hypothalamic-pituitary-adrenal (HPA) axis activity and cortisol levels, changes in immune function, and faster cellular aging. They also found that caregiving was associated with poor sleep quality and

impairments in cognitive functioning. Chiu et al. (2014) also examined sleep disturbance among 180 dyads of family caregivers and individuals with dementia. They found that two-thirds of family caregivers suffered from sleep disturbances in the form of problems with sleep quality, sleepiness in the daytime, and waking up before the sleep cycle ends. Their findings also suggested that a major predictor of sleep disturbance was caregiving stress and depressive symptoms.

One study assessed the cognitive health of dementia caregivers in 192 spousal caregivers of dementia patients and 1,063 spousal caregivers of non-dementia patients (Dassel et al., 2015). The results showed that dementia caregivers had significantly more cognitive decline than non-dementia caregivers when they completed the study in the two biannual waves (or 4 years) prior to their family member's death. Dementia caregivers also had greater cognitive decline than non-dementia caregivers one wave, or two years, following the family member's death. These results suggest that spouses of dementia patients are vulnerable to cognitive decline both during the caregiving stage and after, showing that cognitive changes may be due to an underlying neurological process rather than psychological distress (Dassel et al., 2015). However, a limitation of this study is that it utilized a brief global measure of cognitive function that did not measure all aspects of cognitive function such as language or visuospatial skills (Dassel et al., 2015). In another review of the health effects of dementia caregiving, Fonareva and Oken (2014) also assessed cognitive functioning. Their results showed worse processing speed, delayed verbal recall, executive function, and attention among dementia caregivers in comparison to non-caregivers.

Researchers also have examined risk factors for physical health problems in dementia caregivers. In one meta-analysis of 176 articles, Pinqart and Sorensen (2007) studied correlates of physical health problems in caregivers of older adults. The results showed poor physical health among caregivers was associated with the following factors: (a) longer length of time caregiving, (b) living with an older adult, (c) higher severity of cognitive impairments and behavioral problems in the older adult receiving care, (d) not being a spouse of the person receiving care, (e) higher burden and depression, (f) older age of the caregiver, (g) lower socioeconomic status, and (h) lower levels of support. The relationship was stronger among family members who were caring for an individual with dementia. In a more recent study, Fonareva and Oken (2014) found that vulnerability to health problems in dementia caregivers was influenced by age, gender, ethnic background, neighborhood of residence, childhood abuse, physical activity level, and use of respite services. The results also indicated that health problems were associated with the severity and duration of the dementia patient's symptoms, presence of behavioral symptoms, and the patient's sleep patterns. Additionally, depression was demonstrated to be a risk factor for health problems, as it mediates slowed processing speed, metabolism changes, and sleep impairment.

In contrast, several studies have failed to find higher rates of physical conditions and illness despite caregivers' self-report of poorer physical health (Ory et al., 2000; O'Sullivan et al., 2019; Schulz et al., 1995; Schulz & Martire, 2004). In their review of studies on physical health outcomes in dementia caregivers, Schulz et al. (1995) reported mixed findings on differences between caregivers and non-caregivers in medication use, number of chronic conditions and illness episodes, health care utilization, and health-

related behaviors such as alcohol use, smoking, and sleep. Furthermore, Schulz and Martire (2004) assert that variability in health outcomes among caregivers is mediated by factors such as socioeconomic status, social support, and gender. O’Sullivan et al. (2019) compared the cognitive functioning of dementia caregivers and non-caregivers. Their sample included 252 spouses of dementia patients and two groups of non-caregivers who were matched demographically to the caregiving group. To assess cognitive status, participants were administered the Montreal Cognitive Assessment (MoCA), a choice reaction time test, the color trails test, and measures of category fluency, memory, working memory, depression, and stress. The researchers also measured health and behavioral risk factors for dementia including age, gender, low educational attainment, physical inactivity, obesity, smoking status, history of hypertension and diabetes, depression, frailty, and verbal IQ. The results showed that caregivers had higher reaction time, processing speed, and free recall. There were no differences between caregivers and non-caregivers in working memory, recall, and executive tasks. Furthermore, caregivers did not report consistently higher risk factors than non-caregivers. However, the results did show that caregivers had higher levels of stress and depression (O’Sullivan et al., 2019). These findings are inconsistent with previous studies showing higher cognitive decline among dementia caregivers.

**Psychological Impacts.** Research also suggests that family caregivers of individuals with dementia experience significant emotional distress (Alzheimer’s Association, 2021a; Chirico et al., 2021; Grafstrom & Winblad, 1995; Ory et al., 1999; Ory et al., 2000; Schulz et al., 1995; Schulz & Sherwood, 2008; Svanberg et al., 2011). Several studies found elevated levels of depression and anxiety, as measured by self-



report inventories and diagnostic interviews, in this population (Alzheimer's Association, 2021a; Ory et al., 2000; Schulz et al., 1995; Schulz & Sherwood, 2008; Svanberg et al., 2011). In a sample of 106 caregivers of elderly family members, Clark et al. (2013) found that 54.7% of participants had symptoms consistent with clinical depression based on the Center for Epidemiologic Studies Depression Scale (CES-D). However, only 25% of participants reported having depression, highlighting the discrepancy between individuals who experience symptoms of depression and those who have been diagnosed with it. In their review of the caregiving literature over the previous three decades, Schulz and Sherwood (2008) found that caregivers who reported older age, lower socioeconomic status, and lower social support also reported worse psychological and physical health. One study found women were more likely to have higher depression and anxiety symptoms than male caregivers of individuals with young-onset dementia (Svanberg et al., 2011). Caregivers also experience feelings of loss related to their relationship with the individual with dementia (Alzheimer's Association, 2021a; Svanberg et al., 2011). Moreover, psychological outcomes among family caregivers such as burden, anxiety, and decreased interpersonal contact may be most prominent in the early stages of dementia and when the individual with dementia is still living at home among family members (Grafstrom & Winblad, 1995).

When compared to caregivers of individuals with other illnesses or conditions, dementia caregivers utilize services or resources more often (Crespo et al., 2005; National Alliance for Caregiving & American Association of Retired Persons, 1997; Ory et al., 1999), spend more time on caregiving tasks per week (Ory et al., 1999), have a higher utilization of psychotropic drugs (Schulz et al., 1995), and report less time for

other family members and leisure activities (Grafstrom & Winblad, 1995; National Alliance for Caregiving & American Association of Retired Persons, 1997; Ory et al., 1999), higher stress levels (Grafstrom & Winblad, 1995; National Alliance for Caregiving & American Association of Retired Persons, 1997; Ory et al., 1999), greater need for breaks, and need for financial and social support (National Alliance for Caregiving & American Association of Retired Persons, 1997).

In their meta-analysis of 84 studies, Pinquart and Sorensen (2003) analyzed differences in psychological and physical well-being between caregivers and non-caregivers of older adults. Overall, 58.5% of the caregivers were spouses of the older adult, and 35.8% were adult children. The results showed that caregivers had higher levels of stress and depression and lower levels of subjective well-being, physical health, and self-efficacy than non-caregivers. Furthermore, they found that these differences were significantly larger for dementia caregivers, demonstrating the heightened negative impacts of caring for an individual with dementia. The largest differences were in depression, stress, and self-efficacy. These findings demonstrate the negative psychological effects of family caregiving, particularly when caring for an individual with dementia as compared to other diseases or conditions. In another study, Koyama et al. (2017) compared mental health outcomes among younger and older dementia caregivers. Their sample included 104 dementia caregivers (46 younger than 65 years old and 58 at least 65 years old), as well as 104 non-caregivers matched in age and gender. Results indicated that both younger and older dementia caregivers had lower mental quality of life than non-caregivers. In addition, they found that younger caregivers had significantly more sleep problems than non-caregivers. However, there were no

significant differences in depression between caregivers and non-caregivers as measured by the CES-D for younger participants and the Geriatric Depression Scale (GDS) for older participants.

A more recent study focused on exploring the experiences of family members who function as secondary caregivers to individuals with dementia (Goncalves-Pereira et al., 2020). The sample included 122 participants and consisted of primary caregivers, defined as the individual who provided the most face-to-face contact over the past month, and secondary caregivers, defined as the second nearest person providing care. The results suggest that subjective caregiver burden was higher in primary caregivers; however, it was severe in both groups. Item analysis demonstrated that primary caregivers were more affected by the loss of control over their lives and the patient's dependence on them; whereas secondary caregivers were more impacted by feeling they should do more for the patient's care. Findings also indicated no differences in psychological distress between primary and secondary caregivers, but both groups had elevated scores. The groups also had similar amounts of positive experiences. Further results suggested that secondary caregivers had higher social support than primary caregivers and continued to experience high levels of psychological distress and burden. Based on the findings of this study, the researchers suggest that caring for an individual with dementia can significantly impact multiple family members, and secondary caregivers experience many of the same risks as primary caregivers. Furthermore, high levels of distress may interfere with a secondary caregiver's ability to care for the patient. However, limitations of this study include a small sample size and a nonrandomized sample (Goncalves-Pereira et al., 2020).

In a longitudinal study, Givens et al. (2011) analyzed mental health outcomes of 225 family members of relatives with advanced dementia who were living in nursing homes. The researchers studied family members' exposure to their relatives' distressing symptoms over 18 months and utilized the Stressful Caregiving Adult Reactions to Experiences of Dying (SCARED) scale to measure fear and helplessness associated with exposure. Furthermore, they analyzed the relationship between SCARED scores and depression, psychological distress, and general mental health. Results indicated that the most frequent distressing symptoms of family members were choking, severe pain or discomfort, and thinking their relative had had enough with their symptoms. They found that higher SCARED scores were associated with higher visitation frequency and higher functional impairment in the patient, whereas lower SCARED scores were associated with the resident's comfort and living on a dementia unit. The findings also indicated that family members with higher SCARED scores had higher levels of depression and psychological distress and worse general mental health (Givens et al., 2011).

Weisman de Mamani et al. (2018) studied the impact of stigma on expressed emotion, or caregivers' attitudes and behaviors toward dementia patients. They administered questionnaires to 106 dementia caregivers via telephone, including the Clinical Dementia Rating Scale to determine a dementia diagnosis, the Family Questionnaire to assess expressed emotion, the Quality of Life Inventory, and the Caregiver Stigma Impact Scale. Results suggested that higher stigma was associated with higher expressed emotion, and both higher stigma and expressed emotion were associated with lower quality of life. The findings indicated that caregivers reacted with anger, criticism, and self-sacrificing behaviors when the patient with dementia engaged in

behaviors they perceived as stigmatizing or embarrassing (Weisman de Mamani et al., 2018).

Conversely, another study found nonsignificant differences in emotional state between caregivers of dementia patients and non-dementia patients (Crespo et al., 2005). Crespo et al. (2005) examined 108 primary caregivers who resided with and cared for the patient with dementia for at least 6 months. The researchers used the Activities of Daily Living Scale to measure functional impairment, the Global Deterioration Scale to measure cognitive decline, and the Memory and Behavior Problems Checklist to assess behavioral problems (Crespo et al., 2005). The measures used to assess caregiver outcomes were: (a) the Burden Interview, (b) Caregiving Satisfaction Scale, (c) Rosenberg Self-Esteem Scale, (d) Social Support Questionnaire, (e) Brief-COPE to assess coping strategies, (f) Beck Depression Inventory, and (g) Anxiety Subscale of the Hospital Anxiety and Depression Scale (Crespo et al., 2005). Results indicated no differences in burden, self-esteem, social support satisfaction, or emotion-focused coping between dementia and non-dementia caregivers. However, they did find that depressive symptoms were related to more weekly hours of care, higher burden, more intense reactions to memory and behavior problems, lower self-esteem, less social support, and more emotion-focused coping. They also found that anxiety symptoms were related to higher burden, lower self-esteem, and more emotion-focused coping (Crespo et al., 2005).

**Protective Factors.** Studies have demonstrated possible protective factors and positive experiences of dementia caregiving. In their review of the literature on physical health outcomes in dementia caregiving, Fonareva and Oken (2014) identified physical

activity, diet, stress reactivity, and self-efficacy as possible protective factors for developing health problems. Van Wijngaarden et al. (2018) analyzed experiences of dementia family caregivers from an existential perspective by conducting interviews with 47 family members and six focus groups. Among findings of negative psychological themes, the researchers also identified protective factors that helped some families cope with the dementia. Participants reported benefits from facing and accepting their loved one's dementia, rather than resisting or avoiding it. Furthermore, they emphasized finding meaning in their family member's dementia and valuing the individual's life. They also reported positive outcomes from attempting to maintain connection with their loved one by adjusting to changes as they progressed and embracing the unknown. Finally, participants reported that collaborating with professionals and appreciating support from others contributed to resilience (Van Wijngaarden et al., 2018).

In their review of the existing literature, from the previous 30 years, Schulz and Sherwood (2008) examined the impact of caregiving and identified positive psychological experiences of family caregiving. Findings indicated that caregiving provides meaning for life, affords the opportunity to learn new skills, and strengthens relationships with others. Furthermore, providing support to others can lead to better overall emotional and physical well-being (Schulz & Sherwood, 2008). A more recent study also examined positive psychological experiences (Chirico et al., 2021). Chirico et al. (2021) conducted a systematic review of 21 studies on the experiences of individuals caring for a parent with young onset dementia. Besides negative emotional experiences, the researchers also found that some participants reported positive caregiving experiences including developing maturity and spending more time with their parent than they would

have if they did not have dementia. In addition to caregiver burden, families of dementia patients also experience changes in their relationships and roles that could lead to negative psychological outcomes.

### ***Family Relationships and Roles***

Dementia impacts family relationships and the role individuals play in the family system (Ablitt et al., 2009; Benbow et al., 2019; Celdran et al., 2012; Chan et al., 2012; Chirico et al., 2021; Hall & Sikes, 2018; Lieberman & Fisher, 1999; Youell et al., 2016). Two studies reviewed changes in family relationships including spouses, children, and siblings of the individual with dementia (Ablitt et al., 2009; Benbow et al., 2019). Ablitt et al. (2009) conducted a systematic review of 31 studies assessing relationships between dementia patients and their families. The results showed a decline in the quality of these relationships including negative changes in intimacy, reciprocity, communication, and happiness. Furthermore, the findings showed that lower relationship quality was associated with higher depression in both the family members and the patient with dementia, reduced self-efficacy in the family members, and reduced functional ability in the patient with dementia. However, the researchers also found that some family members reported sustained positive aspects of their relationship including warmth, closeness, and affection. Benbow et al. (2019) also explored changes in family relationships associated with dementia by conducting semi-structured interviews with sisters, husbands, and wives of patients with dementia. Their sample included 13 participants ranging in age from 65 to 82 years. The participants reported increased loneliness, loss of reciprocity in the relationship, feeling the individual was physically there but emotionally absent, changes in intimacy, and negative effects on sexual

intimacy. The results also indicated that the participants' relationships with others were impacted by the presence of dementia. For example, participants reported concern about placing too much burden on their children's lives and putting too much responsibility on children and grandchildren. In addition, participants indicated difficulty interacting with friends due to them not understanding dementia or how to adjust to it. Another finding included changes in the way participants talked about themselves and the person with the dementia, as they began to refer to their relationship as "I" instead of "we" and discussed the dementia patient as if they were a child. Generalizability of this study is limited due to all the participants being White British (Benbow et al., 2019).

A study by Youell et al. (2016) also focused on the experiences of individuals whose partner had dementia. The researchers interviewed six participants, who were in heterosexual long-term relationships with an individual with dementia. Findings indicated that participants endorsed feeling a sense of loss with their partner in everyday activities. Additionally, they reported experiencing a lack of presence, which they described as a slow disappearance of the person even though the person was physically present. The researchers also found that participants felt a loss of reciprocity in communication with their partners that led to difficulty maintaining meaningful conversations. Furthermore, the participants conveyed negative impacts on intimacy and sexual relationships. They described complex thoughts and feelings around these issues and were hesitant to share this information with others (Youell et al., 2016).

Several additional studies explored the experiences of adult children who have a parent with dementia (Chirico et al., 2021; Hall & Sikes, 2018; Lieberman & Fisher, 1999). Lieberman and Fisher (1999) studied the effects of dementia on the family system,



as well as the psychological characteristics that help families manage the stress of dementia, such as family beliefs, practices, organization, and coping strategies. The participants included 78 patients with either Alzheimer's or vascular dementia and their adult children. Findings suggested that higher feelings of burden among adult children were associated with higher strain in their marital relationships, and that male in-laws reported more marital strain. The results also showed that higher marital strain was associated with family characteristics of lower child-adult separation, lower conflict avoidance, higher life engagement, and higher emotional distance. Furthermore, organized family cohesiveness, defined as high levels of organization in the family and closeness among family members, was associated with lower marital strain. These findings demonstrate that the presence of dementia impacts marital relationships in adult children, and certain values and characteristics of the family may serve as protective or risk factors to marital strain (Lieberman & Fisher, 1999).

In a more recent study, Chirico et al. (2021) analyzed the experiences of children (ages 6–35) of early onset dementia patients. The researchers conducted a systematic review of 21 studies and utilized narrative synthesis to identify themes. They found that the diagnosis stage was difficult for the participants triggering confusion, uncertainty, family distress, and feelings of anger, sadness, and fear. However, participants also reported that the diagnosis stage was useful in helping the family understand the causes of their parent's changes and gave them access to support services. The results also showed that children often assumed parental responsibilities, which led to a change in the dynamic of their relationship. The participants reported difficulty dealing with their parent's childlike behaviors and loss of interest in them, leading to feelings of confusion,

fear, and sadness, causing emotional trauma. In addition, children often supported the healthy parent to reduce their burden and experienced changes in their personal lives. For example, managing their parent's dementia led to interruptions in decisions regarding careers and education, as well as decreased time to focus on developing a sense of self. Furthermore, participants acknowledged a lack of social support and neglect by friends, family, and health professionals, especially in cases of early onset dementia (Chirico et al., 2021).

Similarly, a longitudinal study by Hall and Sikes (2018) also focused on experiences of individuals with a parent with dementia. Utilizing an autobiographical approach to identify themes, the researchers conducted three interviews over a 12-month period with 22 children of parents with early onset dementia. The findings suggest that families experienced a disruption to existing family practices and began to view their parent as a child, forcing them to adjust their roles and responsibilities. In addition, participants reported that they maintained their relationship by tending to their parent's needs, valuing small interactions, and assuming responsibility to continue the bond (Hall & Sikes, 2018).

Research also suggests that young people may be impacted when their grandparent suffers from dementia. Celdran et al. (2012) administered questionnaires, which included demographic information, rating scales, and open-ended questions, to 145 adolescents from Barcelona who had a grandparent with dementia to assess how they were affected by the dementia and its impact on relationships with their parents and grandparents. Results indicated that 26.2% of the participants perceived changes to their own lives, such as family routines, values, and emotions, as well as differences in their

communication, affection, and leisure activities with their grandparent with dementia. Furthermore, participants who lived with grandparents were more likely to identify effects on their lives (e.g., changes to family routines, values, and leisure activities). In addition, 32.4% of participants observed changes in their relationship with their parent. Many participants indicated that their parents positively influenced their relationship with their grandparent by encouraging them to remain in contact with their grandparent, teaching them coping strategies, and modeling their own relational behaviors. While 50% of participants indicated positive changes in their relationship with their healthy grandparent (e.g., increase in emotional closeness and frequency of contact), others reported negative outcomes (e.g., less attention from their healthy grandparent and disagreements regarding the dementia; Celdran et al., 2012).

Research also suggests that a family member's comfort and confidence in interacting with their relative with dementia may impact the relationship (Miron et al., 2019). In their quantitative study, Miron et al. (2019) explored the psychological term fear of incompetence, a fear of interacting with certain individuals due to lack of appropriate skills and knowledge. The researchers studied family members' fear of being unable to effectively interact with or care for their loved one with dementia. The participants were 92 individuals who currently had a family member with dementia, including grandchildren, great-grandchildren, nephews and nieces, and other unspecified relatives. Participants completed self-report questionnaires assessing perceived negative changes, severity of symptoms, overall contact, fear of incompetence, perspective taking, negative stereotyping, and desired interaction. The results showed higher fear of incompetence when the relative had more severe symptoms. Additionally, family

members who had a low amount of contact with the relative with dementia had higher fear of incompetence. The researchers also found that higher fear of incompetence was associated with higher negative stereotyping of the dementia patient and lower desire for face-to-face sensory interactions with them (Miron et al., 2019). While dementia affects family relationships and roles, causing psychological distress and relationship strain, families also experience grief and loss for their loved one who is physically there but mentally disappearing.

### ***Grief and Loss***

Research suggests that family members of individuals with dementia experience significant grief and loss (Albinsson & Strang, 2003; Blandin & Pepin, 2017; Boss, 2010; Boss & Yeats, 2014; Chan et al., 2012; Chirico et al., 2021; Hall & Sikes, 2018; Lindgren et al., 1999; Van Wijngaarden et al., 2018). In their systematic review of 31 studies on grief in dementia family caregivers, Chan et al. (2012) found conflicting results on the timing of grief. Certain studies identified higher levels of grief in the later stages of dementia, while other studies demonstrated high levels of grief as early as the time of diagnosis (Chan et al., 2012). Further results indicated persistent grief when the individual was institutionalized, as well as higher grief in spouses. Moreover, in a quantitative study by Lindgren et al. (1999), results showed that overall grief remained constant across the length of caregiving for spouses and children of individuals with dementia. However, caregiver guilt was higher in the early stages of the disease (Lindgren et al., 1999). Studies demonstrate that dementia grief is associated with lower emotional health, including higher rates of depression (Chan et al., 2012; Lindgren et al., 1999). Furthermore, family caregivers may experience complicated post-death grief

(Lindgren et al., 1999). Higher rates of complicated post-death grief are associated with higher depression and burden, lower social support, and being a spouse of the individual (Lindgren et al., 1999). On the other hand, family caregivers who had higher satisfaction with their relationship prior to the dementia onset reported lower grief, anger, and hostility (Lindgren et al., 1999).

Grief associated with dementia is consistently characterized by ambiguity and uncertainty. Several studies report that families describe their loved one as physically present but mentally or psychologically absent (Benbow et al., 2019; Blandin & Pepin, 2017; Chirico et al., 2021; Van Wijngaarden et al., 2018; Youell et al., 2016). Boss (2010) identified this as ambiguous loss, the experience of having a loved one who is both here and gone. This loss is an unusual experience that causes sadness, anxiety, and confusion (Boss & Yeats, 2014) and has been described as the “land of the living death” (Lindgren et al., 1999, p. 535). In the grief process, there is usually closure or verification of the loss, allowing the bereaved to move forward; however, this does not occur in the context of dementia since the grieved person is still physically present (Boss, 2010; Boss & Yeats, 2014). Boss asserted that this type of loss can be traumatic as it hinders the grief process and keeps the family trapped in their current life circumstances (Boss, 2010). Furthermore, this ambiguity continues and reoccurs as losses increase throughout the course of the disease (Boss, 2010). Boss and Yeats (2014) identified several negative impacts of ambiguous loss on the family including immobilization, anxiety, and difficulty communicating and making decisions. In addition, family members may perceive and understand their loved one’s situation differently, leading to family conflict and changes to family roles and practices (Boss & Yeats, 2014). Ambiguous loss can also lead to

depression, anxiety, guilt, helplessness, physical illnesses due to stress, substance use, violence, and identity issues (Boss & Yeats, 2014).

Another aspect of the dementia grief process is anticipatory grief, which occurs when individuals react to the impending loss of their loved one and serial losses that occur before their loved one's actual death (Chan et al., 2012). While anticipatory grief is present in other medical conditions, research suggests it is more significant in dementia due to the cognitive impairments that hinder a patient's awareness and communication, and thus the ability for family members to share feelings and resolve conflict, even in the early stages of the disease (Blandin & Pepin, 2017). In their dementia grief model, Blandin and Pepin (2017) stated that losses increase and get more extensive as dementia progresses. Early on, the patient loses memory and communication and becomes withdrawn, while in the later stages the patient may lose important skills such as driving, cooking, and dressing (Blandin & Pepin, 2017). In addition to losing aspects of the person they have known, family members assume more responsibilities to assist the dementia patient with the skills they have lost (Blandin & Pepin, 2017). Chan et al. (2012) also found that family members reported increased losses as the disease progressed, including loss of intimacy and companionship, personal freedom, control, well-being, and the personhood of the dementia patient. These repeated losses led to feelings of sadness, anger, frustration, and guilt (Chan et al., 2012). Albinsson and Strang (2003) also identified anticipatory grief in their study of existential issues in family members of dementia patients in the palliative stage. In addition, family members reported difficulty dealing with the patient's desire to die, denial of the dementia patient's death, and thoughts about their own life and death.

Research also indicates that the ambiguous loss families of individuals with dementia experience might negatively affect their overall emotional well-being (Albinsson & Strang, 2003; Blandin & Pepin, 2017; Boss, 2010; Boss & Yeats, 2014; Chan et al., 2012; Chirico et al., 2021; Hall & Sikes, 2018; Lindgren et al., 1999; Van Wijngaarden et al., 2018). Therefore, interventions are needed to assist family members with changes that occur as a result of dementia, as well as guide families through the unique grief process that occurs due to ambiguous loss. The current literature on effective intervention strategies was reviewed, and the findings were compiled to construct a cognitive behavioral therapy (CBT) resource manual that family members can utilize to cope with the psychological effects of dementia.

## **Chapter III**

### **Advanced Literature Review**

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

Cognitive behavioral therapy (CBT) was developed in the early 1960s by Aaron Beck, MD, who aimed to design a structured, short-term treatment for depression (Beck, 2011). CBT is often time-limited, present-focused, and targets current problems (Beck, 2011; Thoma et al., 2015), making it a cost-effective treatment (Hofmann et al., 2012). The assumption of CBT is that dysfunctional thinking underlies all psychological disturbances (Beck, 2011). Furthermore, Beck's theory asserts that individuals can improve their emotions and behaviors by evaluating and modifying their thought processes (Beck, 2011). Beck argues that CBT can create long-lasting changes in peoples' lives by teaching individuals coping skills to adjust their underlying beliefs about themselves, others, and the world (Beck, 2011). In the 1990s, the third wave CBT movement occurred which integrated CBT with acceptance, mindfulness, and non-judgmental awareness (Thoma et al., 2015). Third wave CBTs include acceptance and commitment therapy (ACT), dialectical behavior therapy (DBT), and mindfulness-based cognitive therapy (MBCT; Thoma et al., 2015).

Although CBT was originally designed to treat depression, over the years it was adapted to treat diverse populations and mental health problems (Beck, 2011). Research shows that CBT has a strong evidence base and consistently shows positive effects for many people (Beck, 2011; Hofmann et al., 2012; Thoma et al., 2015). Hofmann et al. (2012) conducted a review of 269 quantitative meta-analyses that examined the efficacy of CBT. They found that CBT was consistently effective for anxiety, stress management,



insomnia, and anger and reported mixed efficacy for depression. Another review by Thoma et al. (2015) found that CBT was more effective for depression than no treatment, and CBT combined with medication had larger effects than CBT alone. CBT was found to be more effective than medication alone in producing long-term effects and preventing relapse (Thoma et al., 2015). Many CBT studies, however, are limited by small sample sizes, and they often do not include minority groups or individuals from low-income backgrounds (Hofmann et al., 2012).

### **CBT and Diversity**

Overall, research suggests a lack of diversity in CBT outcome studies, including limited representation from different racial and ethnic groups, sexual orientations, disability statuses, ages, and socioeconomic statuses (Pantalone et al., 2010). Most evidence for CBT is based on middle-class, White, heterosexual individuals; therefore, more research is needed to assess the efficacy of this treatment with diverse populations (Pantalone et al., 2010). Horrell (2008) reviewed 12 studies focusing on the effectiveness of CBT interventions for ethnic minority clients, including adults from African, Asian, and Hispanic/Latino descent. Seven of the studies demonstrated that CBT led to significant improvements in symptoms compared to control and placebo groups. Furthermore, CBT was effective in decreasing symptoms of depression, posttraumatic stress disorder (PTSD), generalized anxiety disorder (GAD), and panic disorder across ethnic groups. However, in one study, African American participants with depression and human immunodeficiency virus (HIV) experienced an increase in depressive symptoms following CBT treatment (Markowitz et al., 2000). Overall, results of Horrell's review show that CBT can be effective with ethnic minority clients, but further research is

necessary to determine the consistent effectiveness of CBT for these groups (Horrell, 2008). Research also suggests that CBT is an effective treatment for depression, anxiety, caregiver distress, and complicated grief, which family members of individuals with dementia often experience (Beck, 2011; Thoma et al., 2015).

### **CBT Interventions for Families of Individuals with Dementia**

Research shows that CBT interventions are effective in reducing negative psychological symptoms and increasing coping abilities in families of individuals with dementia (Cheng et al., 2019; Hopkinson et al., 2019; Verreault et al., 2021; Yorulmaz & Dirik, 2021). Cheng et al. (2019) conducted a systematic review of evidence-based interventions for dementia caregivers. The researchers determined that CBT-based approaches demonstrated the most consistent support for treating caregivers, and particular techniques such as modifying thought processes and increasing behavioral activation were most effective.

Cheng et al. (2019) examined types of CBT-based interventions for treating caregivers of patients with dementia, including psychoeducation on caregiving skills, psychotherapy, multicomponent treatment, and mindfulness-based techniques. Results showed that a combination of CBT and psychoeducation is effective for both in-person and telehealth therapy (Cheng et al., 2019). Additional findings indicated that CBT interventions would help address caregivers' mental health concerns such as depression and anxiety (Cheng et al., 2019). Furthermore, the researchers also noted educational interventions were most helpful immediately after diagnosis, while skills training (e.g., learning to manage behavioral problems, identifying community resources) was more beneficial in the early stages of dementia. During the middle and late stages of dementia,

Cheng et al. suggest that grief-focused interventions and continued skills training would be helpful for caregivers.

In another study, Yorulmaz and Dirik (2021) conducted a systematic review of 20 studies between 1990 and 2020 investigating the effectiveness of CBT interventions for family caregivers of individuals with dementia. Participants consisted of family members and caregivers of a person diagnosed with dementia in many different countries including the United States, Germany, Spain, China, Hong Kong, Italy, Brazil, Pakistan, and the United Kingdom. The interventions utilized were based on CBT. The researchers identified the main components of CBT as psychoeducation, cognitive restructuring, relaxation exercises, problem solving techniques, anger management, assertiveness training, activity scheduling, communication building, stress management, and coping skills for grief and loss. Across the 20 studies, CBT interventions were associated with positive improvements in overall mental health, physical well-being, bodily complaints, cortisol levels, anxiety, depression, anger, stress, burden, self-efficacy, quality of life, coping abilities, dysfunctional thoughts, behavioral activation, problem solving, use of resources, and achievement of goals (Yorulmaz & Dirik, 2021). In addition, interventions were implemented in different ways, such as telephone and Internet, making it possible for caregivers to participate (Yorulmaz & Dirik, 2021).

Two other studies performed meta-analyses to quantitatively evaluate the use of CBT for caregivers of individuals with dementia (Hopkinson et al., 2019; Verreault et al., 2021). Hopkinson et al. (2019) analyzed 25 studies on the effects of group CBT for depression, anxiety, and stress in caregivers. Participants included family members or loved ones of individuals with dementia, ranging in age from 56 to 72 years. The results

showed that caregivers who received group CBT demonstrated statistically significant reductions in depression and stress immediately following treatment in comparison to control groups. There were no significant differences in anxiety following treatment. There were further reductions in depression in the CBT groups at 3-month follow-up; however, stress reductions observed immediately following treatment were not maintained at 3 months. The results also indicated that CBT groups with less than eight sessions were as effective as those with more than eight sessions, which suggests that group CBT with fewer sessions may be practical and effective (Hopkinson et al., 2019), an important finding given cost-related considerations and caregiver availability. Verreault et al. (2021) also conducted a meta-analysis and systematic review examining the efficacy of CBT interventions for dementia caregivers' stress, anxiety, depression, subjective burden, and quality of life in 20 studies. Participants were relatives or close friends who were the main caregivers for an individual diagnosed with a neurocognitive disorder. The CBT interventions included at least one element of cognitive restructuring and one behavioral strategy. Across these studies, the cognitive components included cognitive restructuring, thought modification, emotion modification, and psychoeducation. The behavioral components were problem-solving, behavioral activation, skill-building, relaxation or mindfulness, and self-care. Interventions were implemented in group, individual, and telephone formats. Results indicated significant reductions in subjective burden and depressive symptoms after CBT treatment. There were no significant differences in anxiety and stress between CBT and non-CBT groups. Only one study evaluated quality of life and no statistically significant effects based on the measures used appeared. Participants, however, subjectively reported improved

quality of life following CBT interventions. Overall, this study demonstrates that CBT interventions may be effective in reducing burden and depression in dementia family caregivers (Verreault et al., 2021).

### ***Efficacy of CBT Techniques***

Several studies have evaluated the efficacy of specific CBT techniques for family caregivers (Au et al., 2019; Cheng et al., 2016; Losada et al., 2011; Marquez-Gonzalez et al., 2007). In one study, Marquez-Gonzalez et al. (2007) analyzed the effectiveness of a CBT group intervention focused on modification of dysfunctional thoughts related to caregiving. Participants consisted of 74 spouses, children, and other relatives of individuals with dementia, who were randomly assigned to either the CBT intervention group or the waitlist control group. The intervention consisted of eight 2-hour weekly sessions with eight caregivers per group. The first module of the CBT group intervention focused on dysfunctional thoughts with the goal of detecting and modifying maladaptive thoughts regarding caregiving. This module also included psychoeducation on CBT and cognitive distortions, thought records, and homework assignments. Caregivers' dysfunctional thoughts included, "I should not devote time to my hobbies having a sick relative" and "A caregiver should never make mistakes" (Marquez-Gonzalez et al., 2007; p. 620). During the CBT intervention group, caregivers discussed these dysfunctional thoughts and developed more adaptive ones. For example, participants' modified thoughts included, "Caring for a dependent relative is a complex task which should better be assumed by more than one person" and "Caregivers are not heroes and have the right to make mistakes, to feel angry, sad, or even frustrated" (Marquez-Gonzalez et al., 2007; p. 620). The second module of the CBT group focused on behavioral skills, which

involved teaching specific coping skills to manage caregiving demands. Examples of behavioral skills included seeking help, assertiveness, relaxation techniques, and increasing participation in pleasant activities. The measures utilized were the Center for Epidemiologic Studies Depression Scale (CES-D) for depression, the Memory and Behavior Problems Checklist to assess frequency of problem behaviors and perceived stress, and the Dysfunctional Thoughts About Caregiving Questionnaire to identify dysfunctional thoughts. There were 39 participants who completed the post-intervention interviews. The results demonstrated that at post-intervention the CBT group had lower depression, cognitive appraisal of behavioral problems, and dysfunctional thoughts than the control group. Additionally, participants in the CBT group showed a larger change in dysfunctional thoughts and a greater reduction in depression from baseline to post-intervention. There were no differences in the frequency of behavioral problems in the person with dementia. Finally, the researchers found a mediating effect of dysfunctional thoughts on depression reduction following CBT intervention. These findings highlight the importance of cognitive processes in dementia caregivers' distress and demonstrate the effectiveness of modifying dysfunctional thoughts in reducing depressive symptoms (Marquez-Gonzalez et al., 2007).

Another study by Losada et al. (2011) analyzed the efficacy of adjusting maladaptive thoughts and increasing pleasurable activities for dementia caregivers. These researchers randomly assigned 170 family caregivers to either a CBT intervention group or control group. Participants in the control group received the usual care provided by the recruiting social and health care center. The CBT intervention consisted of 12 weekly group sessions that lasted 1½ to 2 hours. This treatment taught caregivers ways to

acknowledge, analyze, and adjust maladaptive thoughts. Additionally, participants assessed the cognitive barriers that prevented them from engaging in self-care and pleasant activities. Participants were interviewed at baseline and post-intervention, and administered the Dysfunctional Thoughts About Caregiving Questionnaire, the CES-D, and an adaptation of the Leisure Time Satisfaction measure. The findings showed that caregivers in the CBT group had lower scores for depression and dysfunctional thoughts and higher scores for frequency of leisure activities. Furthermore, the results indicated a mediating effect of thought modification and behavioral activities. These findings demonstrate the importance of adjusting cognition and increasing activities for reducing depression in families of dementia patients. One limitation of this study was that researchers did not control for use of medication or other resources during treatment (Losada et al., 2011).

In a more recent study, Au et al. (2019) assessed the effectiveness of a telephone-based psychoeducation and behavioral activation intervention for family caregivers of individuals with Alzheimer's disease. Participants included 96 caregivers recruited from dementia clinics in Hong Kong who were randomly assigned to two conditions: (a) telephone-based psychoeducation and behavioral activation intervention and (b) telephone-based general monitoring with psychoeducation. Both groups received 4 weeks of psychoeducation by a social worker. The intervention group then received eight bi-weekly behavioral activation sessions lasting 20 minutes each. The focus of the 4 weeks of psychoeducation was learning symptoms and stages of dementia, understanding caregiving roles and demands, identifying effects of caregiving and consequences of stress, raising awareness of stress reactions, tracking stressful events and effects on

mood, identifying and scheduling pleasant events, communicating with family members, identifying resources in the community, and future planning. The eight weeks of behavioral activation included completing behavioral monitoring forms, identifying and scheduling pleasant activities, reviewing outcomes and modifying activities, exploring social support, and practicing communication skills. For the control group, the eight weeks of general monitoring involved discussing the participants' health, routines, and social support, as well as the person with dementia's needs. Participants completed the following measures at baseline and post-intervention: (a) Chinese Version of the Disability Assessment for Dementia to assess the functional abilities of the dementia patient, (b) CES-D to measure depression, (c) Zarit Burden Interview to evaluate caregiver burden, (e) Relationship Assessment Scale (RAS) to measure relationship satisfaction, and (f) Self-Efficacy for Controlling Upsetting Thoughts (SE-CU) to assess participants' perceived self-efficacy in controlling thoughts. Results showed that compared to the control group, caregivers in the intervention group scored significantly lower on depression and burden and higher on self-efficacy and relationship satisfaction. Additionally, self-efficacy for controlling upsetting thoughts had a significant partial mediation effect on reduced depression following intervention. These findings demonstrate the effectiveness of a combination of psychoeducation and CBT techniques for mild depression, as well as the ability to administer this intervention via telephone. This allows for cost-effective options and may be more accessible for relatives of individuals with dementia (Au et al., 2019).

In another study, Cheng et al. (2016) evaluated the effectiveness of a gain-focused reappraisal intervention for dementia caregivers. This study included 129 caregivers of



relatives with mild to moderate Alzheimer's disease who provided at least 14 hours of care per week. The caregivers participated in a group format benefit-finding (BF) intervention program. The two control conditions in this study were a standard psychoeducation group, which included the same psychoeducation as the intervention group, and a simplified psychoeducation group, which provided information but did not include skills practice. Each of the three groups had eight weekly 2-hour sessions. Measures were completed before and after treatment and included: (a) Hamilton Depression Rating Scale to measure depression, (b) Zarit Burden Interview to assess caregiver burden, (c) Ryff's Psychological Well-being Scale to assess psychological well-being, (d) Revised Scale for Caregiving Self-Efficacy to measure participants' beliefs about their self-efficacy, and (e) qualitative questions regarding positive gains. The goal of the BF program was to promote positive gains related to caregiving and adjust caregivers' cognitive appraisals. During the intervention, participants discussed stressful situations and generated alternative, more positive appraisals of the situation. Psychoeducation was also integrated, which included information on dementia, awareness of emotions, stress management and relaxation techniques, self-care, activity scheduling, and techniques for assisting patients with symptoms and activities of daily living. Unlike CBT, the BF intervention did not challenge dysfunctional beliefs, rather it focused primarily on increasing positive thoughts. Results indicated significant treatment effects for all outcome measures for BF compared to simplified psychoeducation. The BF group had statistically lower depression and burden when compared to standard psychoeducation. Furthermore, results showed a positive mediating effect of self-efficacy on controlling upsetting thoughts and positive gains. Overall, these results show that

positive reappraisal increased caregivers' confidence in having more positive thoughts, and it may not be necessary to challenge dysfunctional thoughts or core beliefs to achieve positive therapeutic effects (Cheng et al., 2016).

### ***Efficacy of a Telephone-Based CBT Intervention***

Research has examined the effectiveness of telephone-based CBT interventions for caregivers of individuals with dementia. Wilz and Soellner (2016) conducted a randomized controlled trial with 229 adult family caregivers of individuals with dementia. The researchers implemented Tele.TAnDem, a short-term telephone-based CBT treatment developed for dementia caregivers. It consists of psychoeducation and skill building to improve problem-solving skills and coping strategies, increase self-care and positive activities, enhance emotion regulation, practice thought modification, cope with grief and loss, and redefine relationship roles. In this study, the participants attended seven 60-minute sessions conducted over 3 months. The first session was held face-to-face, and subsequent sessions were conducted over the phone. The study included two control groups: (a) a progressive muscle relaxation group and (b) an untreated control group. The researchers administered measures immediately following treatment and at 6-months post-treatment. They utilized the CES-D to assess depression and the Giebener Beschwerdebogen scale to measure physical health complaints. Additionally, they used single-item qualitative questions to assess participants' emotional well-being and perceived health status. Results showed that the CBT group demonstrated significant improvements in emotional well-being compared to both control groups. Additionally, participants in the CBT group showed a reduction in bodily complaints when compared to the untreated control group. There were no significant differences among groups in

depression and perceived health status immediately following the intervention. However, at 6-month follow-up, the CBT group reported significantly better health status when compared to the untreated control group. Additionally, the progressive muscle relaxation group demonstrated a more significant increase in depression over six months than the CBT group. Overall, results demonstrate that the CBT intervention had positive effects for emotional well-being and bodily complaints for caregivers (Wilz & Soellner, 2016). These improvements in emotional well-being and bodily complaints were not present at 6-month follow-up. Participants in the CBT group, however, continued to report improvements in perceived health status and depressive symptoms compared to the control group. Many participants indicated that the treatment was too brief, suggesting that a longer-term intervention may be beneficial (Wilz & Soellner, 2016).

A subsequent study evaluated the effectiveness of the Tele.TAnDem intervention over a longer duration, implementing twelve 50-minute sessions over six months (Wilz et al., 2018). Wilz et al. (2018) randomly assigned 273 family caregivers to the CBT intervention or the control group, who received access to community resources. Findings indicated that participants in the CBT group showed improvements in emotional well-being, depression, physical health, and coping abilities compared to the control group. The positive effects on emotional well-being and coping abilities persisted at 6-month follow-up. The findings of this study also indicate the effectiveness of a CBT telephone intervention with a 6-month duration (Wilz et al., 2018). In a more recent study, Topfer et al. (2021) evaluated the long-term effects of the Tele.TAnDem intervention at 3-year follow-up. Participants included 51 caregivers from the 2018 Wilz et al. study who still provided in-home care to their family member with dementia. The results showed that

participants who received the CBT intervention reported significantly lower burden, higher quality of life with social relationships, and improved coping abilities at 3 years post treatment (Topfer et al. 2021). In conclusion, these studies demonstrate the benefits of a CBT intervention for improving mental well-being and coping abilities for family caregivers of individuals with dementia.

### ***Efficacy of a Computerized CBT Intervention***

Studies have also explored the efficacy of computerized CBT interventions for caregivers of individuals with dementia. Hales and Fossey (2018) studied the Caring for Me and You package, which is a computerized CBT intervention tailored to family caregivers of people with dementia. This transdiagnostic intervention consists of 20 sessions lasting 20 minutes each and includes audio and video commentary along with activities for between sessions. It addresses four common emotions among dementia caregivers: (a) anxiety, (b) depression, (c) guilt, and (d) anger and resentment. This intervention involved helping caregivers understand dementia, learn how individuals respond to stress, recognize and cope with emotions, practice stress management and relaxation techniques, implement problem-solving skills, recognize unhelpful thoughts, and identify supports and resources. Additionally, the intervention is individualized and personalized, allowing participants to select relevant stressors and emotions to work on during the treatment (Hales & Fossey, 2018).

The Caring for Me and You package was evaluated in a randomized controlled trial with 638 participants with depression or anxiety, including family and friends who provided practical or emotional support for individuals with dementia (Fossey et al., 2021). Participants were randomly assigned to one of three conditions: (a) online CBT

with phone support, (b) online CBT without phone support, or (c) online psychoeducation. Participants in the CBT groups completed the computerized sessions of the Caring for Me and You package at their own pace over a period of 26 weeks. The psychoeducation group received materials and fact sheets aimed at promoting their understanding of dementia. Researchers utilized the General Health Questionnaire-12 (GHQ-12) to measure overall mental health at the completion of the 26 weeks. They also administered the following assessments at baseline and post-intervention: (a) the Hospital Anxiety and Depression Scale (HADS) to measure anxiety, depression, and overall mood, (b) the Relative Stress Scale (RSS) to assess caregiver stress, and (c) the Short Sense of Competency Questionnaire (SSCQ) to measure stress affiliated with caregiving. The results showed statistically significant improvements on all outcome measures from baseline to 26 weeks in the online CBT with phone support group. For the online CBT without phone support, findings indicated only significant improvements in overall mental health. For the online psychoeducation group, significant improvements in depression and sense of competency were noted. When analyzing between-group differences, the results showed no significant differences in overall mental health between online CBT with and without phone support and online psychoeducation. Additionally, there were no differences in any outcomes between online CBT with phone support and online psychoeducation. There were, however, significant benefits for mood, depression, and caregiver stress for the online psychoeducation group when compared to the online CBT without phone support group. Overall, this study shows that online CBT without phone support led to significantly less improvement than the online psychoeducation for depression and stress. CBT with phone support, however, had

significant benefits on all measures, and online psychoeducation benefited mental health, depression, and competence. These findings suggest that online psychoeducation should be more widely available for families of dementia patients, and CBT with phone support may have similar benefits (Fossey et al., 2021).

### *Diversity Considerations*

Researchers have explored the effectiveness of interventions for caregivers from diverse populations, as well as the relationship between cultural factors, psychological distress, and coping abilities (Akarsu et al., 2019; Losada et al., 2010). Akarsu et al. (2019) completed a systematic review and meta-analysis of the efficacy of depression interventions for dementia caregivers from ethnic minority backgrounds. They included 13 studies whose participants identified as Latina/Latino American, African American, Chinese American, or “other” ethnicity category. The results indicated that ethnic minority caregivers in the intervention conditions showed significantly lower depression symptoms compared to caregivers in the control conditions. The size of this effect was similar across various interventions (e.g., individual or group psychotherapy, educational interventions, multi-component interventions). Furthermore, studies that recognized the impact of participants’ background and made cultural adaptations were more effective than interventions that did not. For example, one study found that Chinese American caregivers preferred in-home support compared to Latino-Americans, who reported a preference for group or family-oriented approaches. Several relevant cultural factors were identified, including literacy levels, preferred method of treatment (e.g., individual vs. group/family, face-to-face vs. telephone-based), experience with ethnic minorities, and level of social support. These factors may serve as barriers or facilitators to effective

treatment when working with diverse caregivers of individuals with dementia.

Furthermore, caregivers are more likely to engage in treatment if it is adapted to meet their unique needs (Akarsu et al., 2019).

Another study analyzed the influence of sociocultural factors and thought processes on dementia caregivers' depressive symptoms (Losada et al., 2010). Participants, including 334 family caregivers of individuals with dementia, completed face-to-face interviews and were administered the following measures: (a) the Familism Scale to assess familial obligations, perceived family support, and references to family, (b) the Dysfunctional Thoughts About Caregiving Questionnaire to measure maladaptive thoughts, (c) the Psychosocial Support Questionnaire to assess perceived levels of support, (d) the Zarit Burden Interview to measure caregiver burden, and (e) the CES-D to assess depression. The results showed that higher social support was significantly associated with lower depression and burden. Additionally, higher dysfunctional thoughts were significantly correlated with higher familism and depression. These results suggest that cultural values related to family may impact individuals' belief systems and thought processes. Moreover, these findings indicate that having a strong value toward prioritizing family may negatively influence dementia caregivers' well-being (Losada et al., 2010). More specifically, these cultural beliefs may increase maladaptive cognitions related to caregiving, such as rigid thoughts associated with the obligation to sacrifice one's own needs and feelings and completely dedicate oneself to the care of their relative (Losada et al., 2010). However, family values may also have a positive impact on caregiving. For example, caregivers' beliefs regarding family as a source of support may increase their perception of support and decrease depression (Losada et al., 2010).

Overall, this study highlights the importance of considering both cultural and cognitive factors in the treatment of family members who are caring for a loved one with dementia (Losada et al., 2010). In addition to targeting general mental health, CBT treatment has been effective in treating grief and loss in families who have a loved one with dementia.

### **CBT Interventions for Grief and Loss**

Research indicates that CBT is an effective treatment for grief and loss (Kosminksy, 2017). Kosminksy (2017) reviewed the literature on CBT and grief and examined the role of cognition in adapting to the loss of a loved one. The researcher highlights the relationship between thoughts, feelings, and behaviors, and asserts that thoughts about a loved one who has died and an individual's ability to cope with the loss can impact feelings and behaviors. Furthermore, traumatic loss can lead to negative and intrusive thoughts. Findings indicate that rumination hinders the resolution of grief, particularly thoughts that one cannot survive or cope without the family member who has passed. This may lead to a desire to avoid thinking about death, and individuals may tend to engage in more abstract thought processes rather than concrete reasoning and planning. Feelings of guilt and intrusive thoughts can interfere with an individual's ability to carry out daily tasks. This immobilization can further contribute to negative thoughts and feelings. Kosminksy found that CBT treatments for grief aim to help individuals accept their current circumstances. Clinicians use homework assignments to help clients evaluate negative thoughts, re-engage in interpersonal relationships, and decrease avoidance. Additionally, the therapeutic relationship allows for emotional processing and integrating loss into one's sense of self (Kosminksy, 2017).



Various studies examined the effectiveness of CBT for grief in individuals caring for relatives or loved ones with dementia (Meichsner et al., 2016; Meichsner et al., 2019; Meichsner & Wilz, 2018). In one study, Meichsner and Wilz (2018) conducted a randomized controlled trial to study the effects of a CBT intervention on dementia caregivers' abilities to cope with pre-death grief. The participants were 273 spouses, parents, and other family members who were primary in-home caregivers of a person with dementia. They were randomly assigned to either a telephone-based intervention group or a control group. The intervention consisted of twelve 50-minute individual therapy sessions provided by a clinical psychologist via telephone over 6 months. The treatment involved 10 modules that addressed difficult aspects of dementia caregiving, such as modifying dysfunctional thoughts and coping with behavior problems. This study focused on the module that addressed coping with change, loss, and grief. The goal of the sessions was to increase caregiver awareness of perceived changes and losses as well as foster acceptance of the dementia diagnosis and emotions associated with it. Psychologists validated and normalized participants' pre-death grief, provided psychoeducation on avoidance and acceptance, and encouraged participants to verbalize negative emotions. Participants also learned mindfulness skills to increase their conscious experience of painful emotions, as well as engaged in cognitive restructuring of unhelpful thoughts and re-defining relationship roles. Participants in the control group received written information on dementia and caregiving. The researchers administered eight items from the Caregiver Grief Scale (CGS) at baseline, post-intervention, and 6-month follow-up to assess pre-death grief. The results showed that the CBT group had a significant decrease in pre-death grief from baseline to follow-up, and this change was

stronger when compared to the control group. Additionally, caregivers who were caring for their relative at home had lower pre-death grief at post-intervention than those participants who had relatives in a health care facility. This finding was attributed to the significant loss of having a relative placed in a nursing home, as well as the increased amount of time that these family members had to dwell on their losses (Meichsner & Wilz, 2018).

An earlier study by Meichsner et al. (2016) utilized a qualitative content analysis to examine successful interventions to assist caregivers in managing loss and change associated with dementia. The researchers used a previous randomized controlled trial that evaluated a telephone-based CBT intervention for dementia caregivers to further study participants' grief and the interventions clinicians implemented. In this study, the 129 caregivers who had participated in the previous CBT group received seven 50-minute sessions over a 3-month period; whereas the current study focused on the 33 caregivers who had received interventions specifically targeting grief. This included 61 therapy sessions that the researchers transcribed and analyzed. The results showed that therapists most frequently implemented recognition and acceptance of loss. This included loss of communication, intimacy, rituals, and retirement plans. Participants were guided to frame losses as part of the dementia, as well as restructure unhelpful thoughts regarding unrealistic hopes for the future. The findings showed that caregivers had difficulty recognizing or understanding their emotions, so therapists often guided participants to identify difficult feelings, such as anger, guilt, and grief, and connected these feelings to identified losses. Clinicians also highlighted the uniqueness of ambiguous loss and assisted participants in accepting their new reality. A second intervention, addressing

future losses, was frequently utilized in this study. Participants often avoided thinking about the future because it caused severe anxiety. Therapists, therefore, addressed thoughts and feelings regarding the terminal nature of dementia, its final stages, and subsequent death of the loved one. Participants were again guided to accept their inevitable loss, as well as encouraged to plan and find resources to help them cope in the future. A third CBT technique, normalization of grief, involved psychoeducation on grief and validation of painful emotions. In addition, therapists often explained differences between normal grief reactions and depression. Psychoeducation also focused on the benefit of acknowledging grief and the negative consequences of avoidance on both physical and mental health. Furthermore, cognitive restructuring guided participants to address unhelpful assumptions, such as that their negative feelings would never end or that acknowledging their negative feelings would prevent them from caring for their relative. Participants were also encouraged to engage in positive activities. Finally, the intervention of redefining relationships was also utilized in the CBT group. This involved increasing awareness of how family members' roles have changed with the individual with dementia. Overall, qualitative content analysis demonstrated that the CBT intervention helped families accept their losses and facilitated emotional processing. Furthermore, findings also showed that many caregivers have difficulty recognizing and verbalizing their grief (Meichsner et al., 2016).

In another study, Meichsner et al. (2019) examined two individual caregivers and analyzed sources of pre-death grief using the telephone-based Tele.TAnDem CBT intervention. The first case was a 64-year-old woman who cared for her husband with severe vascular dementia for five years. She reported experiencing ambiguous loss, loss

of companionship, and anticipation of future losses. The therapist frequently normalized the participant's grief and guided her to recognize and accept losses. Paraphrasing, psychoeducation, and validation also were implemented. The second case was a 53-year-old woman who cared for her mother with moderate Alzheimer's disease for three years. She also reported anticipation of future losses, ambiguous loss, and loss of companionship. The therapist helped the participant recognize and accept loss and change, normalize grief, address future losses, and redefine the relationship. Overall, both participants reported difficulty coping with the ambiguous losses, particularly loss of companionship. Successful CBT techniques utilized in this study were providing psychoeducation, challenging dysfunctional thoughts, identifying coping strategies, normalizing grief, addressing painful emotions, and overcoming avoidance (Meichsner et al., 2019). Additionally, findings indicated that caregivers may be unaware of their ambiguous loss and lack skills needed to manage grief, which may lead to avoidance of thoughts and emotions and cause physical symptoms (e.g., upset stomach, nausea, headache, fatigue). This study also highlights the importance of teaching caregivers the difference between short-term distraction and relief, such as respite services, and ongoing avoidance of losses (Meichsner et al., 2019). However, this study has limited generalizability due to its case study format and inclusion of only female participants (Meichsner et al., 2019).

### ***Applying CBT to the Dementia Grief Model***

The dementia grief model (Blandin & Pepin, 2017) highlights the unique grief process for caregivers of individuals with dementia. This model has three stages: (a) Separation, (b) Liminality, and (c) Re-emergence. In the Separation stage, family

members experience compounded losses that separate them from the person with dementia (Blandin & Pepin, 2017). These losses increase and become more expansive as the disease progresses. For example, the early stages of dementia may include loss of memory, communication, and engagement, while in the later stages of the disease, individuals with dementia may lose their ability to drive, cook, and dress. The dynamic mechanism in this stage is acknowledgement of loss, which facilitates movement through the grief process. Blandin and Pepin assert that movement from this stage may be inhibited if families do not recognize, resist, or deny the loss. The Liminality stage of the dementia grief model is marked by ambiguity and uncertainty. During this stage, caregivers are grieving previous losses, anticipating future stressors, and experiencing ongoing grief. Because dementia typically has a long prognosis, this experience of ambiguity and uncertainty is often prolonged throughout the lengthy course of the disease. The dynamic mechanism in this stage is tolerating difficult feelings, which may be inhibited if family members avoid or suppress their feelings (Blandin & Pepin, 2017). The dementia grief model's final stage, Re-emergence, occurs when caregivers acknowledge, understand, and accept losses, as well as experience feelings of closure and stability (Blandin & Pepin, 2017). The dynamic mechanism in this stage is adaptation, which includes adapting to loss and making changes in everyday life. Blandin and Pepin assert that the dementia grief model is a cycle that continues to be repeated until the individual with dementia passes away.

In Meichsner et al. (2019)'s study that analyzed pre-death grief, CBT interventions corresponded with the mechanisms of action in the dementia grief model. For example, recognizing and accepting loss and change corresponds to the Separation

stage (Meichsner et al., 2019). During CBT treatment, caregivers were guided to acknowledge their losses and process their emotions. Furthermore, the CBT study found that participants tended to avoid negative feelings and situations, causing long-term consequences to their physical and mental health, which is consistent with the Liminality stage of the dementia grief model. CBT interventions helped caregivers normalize and express their emotions, address unhelpful thoughts, and identify resources to cope with difficult feelings and situations. Finally, in the CBT study, caregivers displayed changed behaviors including using new coping skills and resources and engaging in acceptance behaviors, rather than avoidance (Meichsner et al., 2019). This finding corresponds to the concept of adaptation and the Re-emergence stage of the dementia grief model (Meichsner et al., 2019). The study also found that dementia grief occurred in a cycle, which is consistent with the dementia grief model (Meichsner et al., 2019). Participants reported new and reoccurring losses throughout the treatment, and they were guided to repeatedly address their feelings and apply CBT interventions (Meichsner et al., 2019).

### **Conclusion**

For families and loved ones of individuals with dementia, CBT interventions effectively reduce negative psychological and physical symptoms associated with caregiving stress, and increase coping strategies (Au et al., 2019; Cheng et al., 2016; Cheng et al., 2019; Fossey et al., 2021; Hopkinson et al., 2019; Losada et al., 2011; Marquez-Gonzalez et al., 2007; Meichsner et al., 2016; Meichsner et al., 2019; Meichsner & Wilz, 2018; Topfer et al., 2021; Verreault et al., 2021; Wilz et al., 2018; Wilz & Soellner, 2016; Yorulmaz & Dirik, 2021). Applicable CBT components include psychoeducation, cognitive restructuring, behavioral activation, and self-care and stress

management techniques (Au et al., 2019; Cheng et al., 2019; Fossey et al., 2021; Losada et al., 2011; Marquez-Gonzalez et al., 2007; Meichsner et al., 2016; Meichsner et al., 2019; Meichsner & Wilz, 2018; Topfer et al., 2021; Verreault et al., 2021; Wilz et al., 2018; Wilz & Soellner, 2016; Yorulmaz & Dirik, 2021). Interventions also target unique experiences of anticipatory grief and ambiguous loss associated with dementia, as illustrated in the dementia grief model (Blandin & Pepin, 2017; Meichsner et al., 2016; Meichsner et al., 2019; Meichsner & Wilz, 2018). Research shows that CBT interventions can be implemented effectively in face-to-face individual and group formats, as well as via telephone and internet-based modalities (Cheng et al., 2019; Yorulmaz & Dirik, 2021). Given the time commitments and financial demands associated with caring for a loved one with dementia, families would likely benefit from flexible and accessible interventions (Alzheimer's Association, 2021a; Mather & Scommegna, 2020; Yorulmaz & Dirik, 2021). Therefore, self-help resources that integrate psychoeducation and evidence-based CBT interventions may be beneficial to assist families in understanding dementia and managing difficult stressors, thoughts, and emotions. These resources also may help to normalize mental health treatment and encourage families to participate in more intensive and guided psychological treatments, such as psychotherapy or support groups.

## Chapter IV

### Discussion

#### Introduction

Families caring for a loved one with dementia experience significant psychological distress and a unique grief process. Therefore, they need education and resources tailored to their experience to assist them in managing the stress of caregiving. Because caregiving is financially demanding and time-consuming, accessible resources that family members can utilize independently increase their opportunities to receive education and coping skills. Therefore, a self-help resource that incorporates evidence-based interventions would likely be an appropriate and effective intervention tool for this population. In this chapter, a new self-help manual designed for adults who have a family member, friend, or loved one with dementia is proposed. This resource provides information on dementia and teaches coping skills that families can use in their everyday lives. CBT is an evidence-based and effective treatment for family caregivers; therefore, the proposed manual includes CBT interventions to address caregiver stress and dementia-related grief.

#### A Proposed Self-Help Manual for Coping with Dementia

This review examined the research on the psychological effects of having a loved one with dementia and the effectiveness of CBT interventions for reducing psychological distress. Based on the research findings, a self-help manual, *Coping with Dementia: A Resource for Families and Loved Ones*, was constructed. The manual is divided into eight chapters (see Table 1) that provide education and teach coping strategies.



**Table 1***Table of Contents*

| Chapter                                | Description  |
|--|--|
| Chapter 1: What is Dementia?           | Chapter 1 defines dementia and presents the symptoms of the most common types.   |
| Chapter 2: All About Family Caregiving | Chapter 2 describes common caregiving tasks and explains the financial, physical, and psychological effects of dementia caregiving.  |
| Chapter 3: The Unique Grief Process    | Chapter 3 explains the components of dementia grief, including ambiguous loss and anticipatory grief. The Dementia Grief Model (Blandin & Pepin, 2017) is also presented.  |
| Chapter 4: What is CBT?                | Chapter 4 introduces Cognitive Behavioral Therapy (CBT) and explains its assumptions, components, and goals.   |
| Chapter 5: Recognizing Your Thoughts   | Chapter 5 teaches common negative thinking patterns and cognitive restructuring techniques, including thought records and Socratic Questioning. This chapter provides specific examples of unhelpful thoughts related to caregiving. |
| Chapter 6: Understanding Your Feelings | Chapter 6 describes emotional processing techniques and normalizes common emotions associated with dementia including anxiety, depression, guilt, and anger.   |
| Chapter 7: Improving Your Behaviors    | Chapter 7 teaches behavioral activation skills to increase positive activities. It also describes stress management skills including relaxation techniques and respite services. Finally, this chapter provides skills for managing  |

| Chapter                         | Description   |
|---------------------------------|---|
|                                 | challenging behaviors in the person with dementia.  |
| Chapter 8: Additional Resources | Chapter 8 provides additional resources for dementia including organizations, support groups, and phone apps. |

In accordance with the research, four CBT-based components are included throughout the manual: (a) psychoeducation, (b) thought modification, (c) emotional processing, and (d) behavioral activation and stress management.

### ***Psychoeducation***

Several effective CBT intervention studies for family caregivers included psychoeducation as a primary component (Au et al., 2019; Cheng et al., 2016; Cheng et al., 2019; Fossey et al., 2021; Marquez-Gonzalez et al., 2007; Meichsner et al., 2016; Meichsner et al., 2019; Meichsner & Wilz, 2018; Topfer et al., 2021; Verreault et al., 2021; Wilz et al., 2018; Wilz & Soellner, 2016; Yorulmaz & Dirik, 2021). In these studies, psychoeducation helped families learn about dementia, caregiver stress, and CBT techniques to manage distressing thoughts, feelings, and behaviors. Because psychoeducation may be most helpful in the early stages of dementia following diagnosis (Cheng et al., 2019) and is a vital component of any CBT-based intervention, the first four chapters of the proposed manual focus on psychoeducation. In these chapters, psychoeducation is provided on the definition and symptoms of dementia, common caregiving tasks, the effect of dementia on families and loved ones, and the components of CBT.

**Chapter 1: What is Dementia?** To increase the family's understanding of the loved one's disease, the first chapter provides psychoeducation on the definition and symptoms of dementia. The manual describes the areas of cognition that can be impacted by dementia, such as memory, attention, ability to speak and understand language, motor and visual skills, and executive functioning (e.g., planning, organization, self-regulation, and self-control). It also explains the difference between dementia and normal aging, as well as the changes to personality and behaviors that can occur in dementia. Next, the proposed manual provides a brief overview of the common types of dementia, including Alzheimer's disease, vascular dementia, frontotemporal dementia, dementia with Lewy bodies, and Parkinson's disease. This is presented as a bulleted list of the common symptoms and prognosis of each dementia type. This familiarizes families with the specific form of dementia their loved one has and its accompanying symptoms and behaviors.

**Chapter 2: All About Family Caregiving.** In the second chapter, families receive information on the common tasks of dementia caregiving, as well as the financial, physical, and psychological effects dementia can have on families and loved ones. This psychoeducation will increase awareness of possible negative impacts dementia can have on the family, as well as normalizes these experiences and the need for coping skills and resources.

**Chapter 3: The Unique Grief Process.** The third chapter includes psychoeducation on the unique grief process associated with dementia. Several components of dementia grief are explained in this chapter to normalize the unique grief experiences that occur in the context of dementia. First, families are provided with

psychoeducation on ambiguous loss, a common experience among families and loved ones of individuals with dementia (Boss, 2010). The manual defines ambiguous loss and discusses the psychological effects it can cause such as sadness, anxiety, depression, guilt, helplessness, and confusion. Next, anticipatory grief is defined as another common experience among families (Chan et al., 2012). Examples of repeated losses are provided, such as loss of intimacy and companionship, personal freedom, well-being, and the personhood of the loved one with dementia. This chapter also cautions that anticipatory grief can be more significant in the context of dementia than in families of individuals with other medical conditions (Blandin & Pepin, 2017). Finally, this chapter provides psychoeducation on the Dementia Grief Model (Blandin & Pepin, 2017) to highlight the unique stages that occur in the context of dementia. The stages, psychological states, and dynamic mechanisms are presented in a table format to facilitate families' understanding of the model (see Appendix A).

**Chapter 4: What is CBT?** In the fourth chapter, families receive psychoeducation on the definition, assumptions, and components of CBT. This information familiarizes them with CBT interventions and provides an introduction to the remainder of the manual. This is an important part of CBT treatment to ensure that individuals understand and are interested in engaging in the interventions. First, the manual explains CBT, its benefits, and its efficacy. Next, the relationship between thoughts, feelings, and behaviors is described, and a figure of Beck's (2011) cognitive triangle is included to illustrate this concept. The manual explains the main goal of CBT is to modify thought processes. In addition, families learn that according to CBT, changing the way they think will lead to feeling better and acting more effectively.

Overall, this chapter introduces CBT and provides the knowledge needed to learn and practice specific CBT skills.

### ***Thought Modification***

Research indicates that thought modification is an effective and important CBT intervention for families of individuals with dementia (Cheng et al., 2019; Fossey et al., 2021; Losada et al., 2011; Marquez-Gonzalez et al., 2007; Meichsner et al., 2016; Meichsner et al., 2019; Meichsner & Wilz, 2018; Topfer et al., 2021; Verreault et al., 2021; Wilz et al., 2018; Wilz & Soellner, 2016; Yorulmaz & Dirik, 2021). In these studies, family caregivers learned to recognize, evaluate, and modify their thoughts. The proposed manual, therefore, includes a chapter on awareness of cognitive processes and modification of unhelpful thoughts related to dementia.

**Chapter 5: Recognizing Your Thoughts.** This chapter begins by explaining the first step of thought modification, gaining awareness of thoughts. It introduces thought records as a way to track thinking patterns throughout everyday life (Beck, 2011; Dobson & Dobson, 2017). The manual guides families to record their thoughts when they are experiencing a stressful event or negative mood. Families are encouraged to reflect on what situations tend to cause stress, how they interpret stressful situations, the emotions they commonly feel, and the actions they take after a stressful event occurs (Beck, 2011; Melemis, 2021). The thought record technique is included in the manual to help families apply CBT tenets to their everyday lives.

This chapter also provides psychoeducation on cognitive distortions. Table 2 provides definitions of common cognitive distortions based on Beck (2011) and Dobson and Dobson (2017). Furthermore, examples of each cognitive distortion were created to

apply specifically to family caregivers. This table will increase awareness of unhelpful thought patterns in the context of caring for a loved one with dementia.

**Table 2**

*Common Unhelpful Thinking Styles*

| Cognitive Distortion (Beck, 2011; Dobson & Dobson, 2017) | Description (Beck, 2011; Dobson & Dobson, 2017)  | Example  |
|--|--|--|
| All-or-Nothing Thinking                                  | Viewing situations in only two categories instead of on a continuum  | “If I’m not perfect as a caregiver, I’m a failure.”  |
| Catastrophizing  | Predicting the future in a negative manner without considering more likely outcomes                                  | “If I lose my loved one, I won’t be able to function at all.”  |
| Disqualifying the Positive                               | Telling yourself that positive experiences or qualities don’t count  | “I completed that caregiving task well, but I just got lucky.”   |
| Emotional Reasoning                                      | Thinking something must be true because you feel it strongly, and ignoring or discounting contrary evidence          | “It feels like I’m doing a bad job, so I must be a bad caregiver.”   |
| Labeling   | Placing a fixed, general label on yourself or others without considering specific evidence                           | “I’m a lazy caregiver.”  |
| Magnification/Minimization                               | Magnifying negative information and minimizing positive information when evaluating yourself, others, or a situation | “I reacted angrily and lost control with my spouse, which shows I’m a bad caregiver.”<br><br>(Minimizing the positive things, you did to handle the situation, |

| Cognitive Distortion (Beck, 2011; Dobson & Dobson, 2017) | Description (Beck, 2011; Dobson & Dobson, 2017)   | Example   |
|--|---|---|
|  |   | such as being a source of support and demonstrating active listening)   |
| Mental Filter  | Paying unreasonable attention to one negative detail instead of seeing the whole picture                                    | “Because my parent got angry with me yesterday, it means they don’t love me.”<br><br>(Ignoring the several positive interactions with your parent that also occurred yesterday) |
| Mind Reading   | Believing you know what others are thinking and failing to consider other possibilities                                     | “My family members think I’m not competent enough to deal with these caregiving tasks.”   |
| Overgeneralization                                       | Making a general negative conclusion that goes beyond the current situation   | “Because I wasn’t able to stop my loved one from wandering last night, I don’t have what it takes to be a caregiver.”   |
| Personalization  | Believing you are the cause of negative things or others’ negative behaviors without examining other causes or explanations | “The doctor was short with us because I did something wrong.”   |
| “Should” and “Must” Statements                           | Having fixed ideas of how you or others should behave, and  | “I should be there for my loved one all the time,   |

| Cognitive Distortion (Beck, 2011; Dobson & Dobson, 2017) | Description (Beck, 2011; Dobson & Dobson, 2017)                  | Example                                 |
|--|--|---|
|  | overestimating how bad it is when these expectations are not met | and I’m a bad person for not doing so.” |

In addition, psychoeducation is provided on common unhelpful thoughts among family caregivers (Montorio et al., 2009). Examples of common negative thoughts among caregivers are provided, and families are guided to reflect on how these thoughts appear to their lives (see Appendix B).

Next, the proposed manual introduces cognitive restructuring techniques to modify negative thoughts and generate alternative ones. Families learn Socratic Questioning techniques (Beck, 2011; Dobson & Dobson, 2017) to evaluate their negative thoughts. For example, they are guided to ask themselves what evidence supports and does not support the thought, if there is an alternative viewpoint or perspective, what the worst thing is that could happen and how they would cope with it, and what they would tell a friend or family member in the same situation. Then, families learn to develop more balanced, realistic thoughts. Table 3 demonstrates this skill in the context of family caregiving.

**Table 3**

*Modifying Negative Thoughts*

| Negative Thought                   | Alternative Thought   |
|------------------------------------|---|
| If I’m not perfect, I’m a failure. | I’m doing the best that I can. Everyone makes mistakes, and I’m learning from them. |



| Negative Thought  | Alternative Thought  |
|---|--|
| If I lose my parent, I won't be able to function at all.                            | Losing my parent would be a difficult experience, and I am working to develop the coping skills and resources to get through it.                   |
| I completed a task well, but I just got lucky.                                      | I performed the task well, and I am giving myself credit for the effort that I gave.   |
| It feels like I'm doing a bad job, so I must be a bad caregiver.                    | Even though it feels like I'm doing a bad job, the fact that my loved one is safe and supported shows that I'm not a bad caregiver.                |
| I'm lazy.   | I'm tired and overwhelmed, which makes it difficult for me to complete all the tasks and activities that I want to do.                             |
| I reacted angrily and lost control with my spouse, which shows I'm a bad caregiver. | I made a mistake by losing my patience with my spouse, but I also did well as a caregiver when I supported them and listened to their needs.       |
| Because my parent got angry with me yesterday, it means they don't love me.         | It was upsetting when my parent got angry with me yesterday, but we had many positive interactions throughout the day that show their love for me. |

This intervention encourages families to practice modifying negative thoughts and increasing positive and reality-based thinking, which decreases psychological distress associated with dementia (Cheng et al., 2016). Families are encouraged to practice identifying their strengths and engage in gratitude exercises to help focus on the positive aspects of their lives.

Finally, this chapter teaches families to reframe thoughts to accept and acknowledge loss and change, which the literature shows is effective for addressing grief in dementia (Blandin & Pepin, 2017; Meichsner et al., 2016; Meichsner et al., 2019;

Meichsner & Wilz, 2018). Loved ones are guided to identify their losses, changes in their lives, their new roles in their relationship, if they are denying or avoiding changes, and resources to cope with future losses. Families are encouraged to practice acknowledging how they can live in their current reality and adapt their behaviors to the changes, rather than avoiding or denying them. Furthermore, they are taught to continue reflecting on losses as they re-occur. This skill helps families move through the dementia grief process and reduce psychological distress (Blandin & Pepin, 2017; Meichsner et al., 2019).

### ***Emotional Processing***

Emotional processing is an important component of CBT interventions for family caregivers of individuals with dementia. It guides families to recognize, identify, and regulate their emotions (Cheng et al., 2016; Hales & Fossey, 2018; Meichsner et al., 2016; Meichsner et al., 2019; Meichsner & Wilz, 2018; Wilz & Soellner, 2016). Research shows that loved ones often have difficulty expressing their emotions related to dementia, especially grief reactions (Meichsner et al., 2016). Furthermore, research demonstrates that addressing difficult and painful feelings can lead to improved well-being (Blandin & Pepin, 2017; Kosminksy, 2017; Meichsner et al., 2016; Meichsner et al., 2019; Meichsner & Wilz, 2018). Therefore, the proposed manual attempts to normalize a wide range of emotions and encourage emotional expression.

**Chapter 6: Understanding Your Feelings.** Because research indicates that anxiety, depression, guilt, anger and resentment are the most common emotions among family members of individuals with dementia (Hales & Fossey, 2018), this chapter focuses on validating and normalizing these emotions. These difficult feelings are

described, and examples of related situations, thoughts, and behaviors are provided (see Table 4).

**Table 4**

*Common Emotions for Families Dealing with Dementia*

| Emotion    | Description  |
|------------|--|
| Anxiety    | <p>Can arise from worries about the future, concern for your loved one's health, and the unpredictability of dementia.</p> <p>Can look like difficulty controlling worry and frequently anticipating stressors or problems.</p> <p>Can manifest in restlessness, fatigue, difficulty concentrating, irritability, muscle tension, and difficulties sleeping.</p> <p>Can lead to avoidance of stressors and acknowledging feelings, which has long-term consequences on mental and physical health.</p> |
| Depression | <p>You may feel sadness regarding the loss of your loved one's abilities and personality, hopelessness for the future, and a loss of interest in activities you used to enjoy.</p> <p>Depression can also lead to difficulties concentrating, difficulties sleeping, changes to your appetite, and decreased energy and motivation.</p> <p>You may have negative thoughts about yourself and the future.</p>   |

| Emotion              | Description  |
|----------------------|--|
| Guilt                | <p data-bbox="865 285 1390 499">Guilt may arise from thoughts about placing your loved one in a nursing home, not providing enough care or sacrificing enough time for your loved one, and conflicts with your loved one before the dementia was diagnosed.</p> <p data-bbox="865 541 1414 611">You may feel guilty for needing a break or accepting help from others.</p> <p data-bbox="865 653 1390 827">You may also experience guilt related to thoughts about your loved one's death, losing your patience with them, or feeling embarrassed or disgusted by their behavior.</p> <p data-bbox="865 869 1365 1010">Feelings of guilt can create intrusive thoughts, impact your ability to complete daily tasks, and hinder you from experiencing positive feelings.</p> |
| Anger and Resentment | <p data-bbox="865 1094 1390 1192">You may feel anger in reaction to the diagnosis of dementia and questioning why it had to happen.</p> <p data-bbox="865 1234 1398 1339">Caregivers may also feel anger and resentment for having to give up things in their lives to care for their loved one.</p> <p data-bbox="865 1381 1390 1598">Additionally, you may feel anger in response to the individual's behavioral problems, or in response to health professionals' and other family members' decisions and reactions to your loved one.</p> <p data-bbox="865 1640 1406 1703">You may also resent other people who are not dealing with dementia.</p>  |

Loved ones are encouraged to acknowledge and process these emotions by verbalizing or journaling them. Additionally, families are reminded that positive emotions can increase when negative thought processes are evaluated and adjusted.

### ***Behavioral Activation and Stress Management***

Research has also demonstrated the effectiveness of behavioral strategies, such as behavioral activation and stress management techniques, for families of individuals with dementia (Au et al., 2019; Fossey et al., 2021; Hales & Fossey, 2018; Losada et al., 2011; Meichsner et al., 2016; Meichsner & Wilz, 2018; Topfer et al., 2021; Verreault et al., 2021; Wilz et al., 2018; Wilz & Soellner, 2016; Yorulmaz & Dirik, 2021). Behavioral activation helps improve family members' thoughts and emotions by teaching them to engage in positive behaviors and self-care techniques (Beck, 2011). It also improves self-efficacy (Beck, 2011). Stress management techniques help family caregivers reduce elevated stress levels that negatively affect their mental and physical well-being (Dobson & Dobson, 2017). The manual, therefore, includes a chapter focused on teaching behavioral strategies to manage stressors and improve family members' well-being while caring for their loved one with dementia. Also in this chapter, families are provided with information on respite care services, a provider of short-term relief for caregivers (Alzheimer's Association, 2007).

**Chapter 7: Improving Your Behaviors.** This chapter first defines behavioral activation and explains its purpose and benefits (see Appendix C). Next, the steps of behavioral activation are explained, and a sample schedule is provided for families to practice scheduling positive activities (see Figure C1). Also in this chapter, respite care is defined as a short time of relief for caregivers to receive a break while the person with

dementia continues to receive care (Alzheimer's Association, 2007). The manual explains different types of respite services, including in-home respite care, adult day centers, residential care, and informal respite care (see Appendix D). It also highlights that although respite services may not be covered by insurance, financial assistance may be available through various programs, such as local Alzheimer's Association chapters. Additional financial resources are presented in the final section of the manual.

Relaxation techniques are introduced as a way to manage stress and reduce physical tension. Families are encouraged to practice these strategies to gain awareness of their stress reactions and to determine which techniques are most effective for them. The manual provides instructions and videos for several relaxation techniques including progressive muscle relaxation, breathing exercises, mindfulness meditation, and guided imagery or visualization (see Appendix E).

This chapter identified skills caregivers can develop to help them manage the challenging behaviors of the person with dementia. Caregivers are provided with examples of difficult behaviors that may occur during the course of dementia, including agitation, aggression, depression, paranoia, hallucinations and delusions, and pacing and wandering (American Psychiatric Association, 2022; James et al., 2020; National Institute on Aging, 2019). The manual addresses many different factors that cause an individual to engage in difficult behaviors, including physical health issues (e.g., pain, lack of sleep, side effects of new medications, infections, or co-morbid medical conditions such as diabetes), emotional issues (e.g., depression, anxiety, loneliness, fear, or confusion), and environmental issues (e.g., being in an unfamiliar or restrictive environment, too much noise, temperature changes, or verbal or non-verbal behaviors by

other people; James et al., 2020; National Institute on Aging, 2019). Behavioral skills, such as communication strategies and de-escalation techniques, to prevent and manage behavioral difficulties in a loved one with dementia are presented (see Appendix F).

### ***Additional Resources***

**Chapter 8: Additional Resources.** The final chapter of the manual provides a list of resources for further support including dementia organizations, helplines, support groups, psychotherapy, phone apps, and financial resources (see Appendix G). This information is included to encourage families to seek additional resources beyond this manual to assist them in coping with dementia.

### **Clinical Implications**

Many family caregivers are suffering from mental and physical health symptoms, and healthcare professionals are likely to encounter these individuals in doctor's offices, hospitals, and nursing homes. Families, however, may not realize their symptoms are related to dementia caregiving. Furthermore, these symptoms may be overlooked by health professionals who are focused on treating the individual with dementia. Therefore, it would be beneficial for health professionals to include families and loved ones in treatment planning, as well as provide families with education and support. Health facilities that frequently treat individuals with dementia may benefit from having resources on hand to provide families and loved ones, who can then use it on their own time and at their own pace. The proposed manual from this research is an example of a resource that provides education and emotional support to families of individuals with dementia. When treating patients with dementia, clinicians may give the self-help resource to families to provide information and coping skills. This manual would benefit

families by providing education that is easy to understand, normalizing and validating difficult thoughts and emotions, and teaching evidence-supported coping skills to manage the psychological impacts of dementia. These skills would help families cope with the devastating effects of dementia and improve their ability to provide necessary care to their loved one.

### **Limitations of the Study**

This project reviewed existing literature on caregivers of a loved one with dementia. A proposed self-help manual was developed. The manual was not printed or piloted. Therefore, the efficacy of the self-help manual intervention cannot be determined. Future research is needed to assess the effectiveness of this resource for families and caregivers among diverse populations.

### **Future Directions**

Because of the increasing number of individuals diagnosed with dementia, there is a need for continued research on the impacts of this disease on families and loved ones. Furthermore, researchers need to continue studying flexible and accessible interventions for families given the significant financial and time demands of dementia caregiving. The proposed manual can be used in future research to assess the effectiveness of self-help resources and identify helpful interventions for family caregivers. A variety of health care settings may benefit from utilizing this intervention when treating families with a dementia diagnosis, and future research could identify the types of settings that need these resources. Furthermore, with growing research on telehealth and electronic resources, researchers may consider exploring treatments that can be implemented in diverse formats to reach a variety of families. Overall, health care professionals must



strive to inform families about dementia and offer helpful support to loved ones who are providing essential care to individuals with dementia.

### References

- Ablitt, A., Jones, G. V., & Muers, J. (2009). Living with dementia: A systematic review of the influence of relationship factors. *Aging and Mental Health, 13*(4), 497–511. <https://doi.org/10.1080/13607860902774436>
- Akarsu, N. E., Prince, M. J., Lawrence, V. C., & Das-Munshi, J. (2019). Depression in carers of people with dementia from a minority ethnic background: Systematic review and meta-analysis of randomised controlled trials of psychosocial interventions. *International Journal of Geriatric Psychiatry, 34*(6), 790–806. <https://doi.org/10.1002/gps.5070>
- Albinsson, L., & Strang, P. (2003). Existential concerns of families of late-stage dementia patients: Questions of freedom, choices, isolation, death, and meaning. *Journal of Palliative Medicine, 6*(2), 225–235. <https://doi.org/10.1089/109662103764978470>
- Alzheimer's Association. (2007). *Respite care guide: Finding what's best for you*. [https://www.aoascc.org/Content/www/CMS/files/info\\_library/brochure\\_respitecareguide.pdf](https://www.aoascc.org/Content/www/CMS/files/info_library/brochure_respitecareguide.pdf)
- Alzheimer's Association. (2021a). 2021 Alzheimer's disease facts and figures. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association, 17*(3), 327–406. <https://doi.org/10.1002/alz.12328>
- Alzheimer's Association. (2021b, March 2). *Bipartisan legislation to expand caregiver training and support introduced in 117<sup>th</sup> congress*. <https://www.alz.org/news/2021/bipartisan-legislation-to-expand-caregiver-trainin>

Alzheimer's Society. (2021, June 18). *The later stage of dementia*.

<https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/how-dementia-progresses/later-stages-dementia#content-start>

American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental*

*disorders* (5th ed., text rev.). <https://doi.org/10.1176/appi.books.9780890425787>

American Psychological Association. (2019, October 30). *Mindfulness meditation: A*

*research-proven way to reduce stress*.

<https://www.apa.org/topics/mindfulness/meditation>

Au, A., Yip, H.-M., Lai, S., Ngai, S., Cheng, S.-T., Losada, A., Thompson, L., Gallagher-

Thompson, D. (2019). Telephone-based behavioral activation intervention for

dementia family caregivers: Outcomes and mediation effect of a randomized

controlled trial. *Patient Education and Counseling*, *102*(11), 2049–2059.

<https://doi.org/10.1016/j.pec.2019.06.009>

Beck, J. S. (2011). *Cognitive behavior therapy: Basics and beyond* (2nd ed.). Guilford

Press.

Benbow, S. M., Tsaroucha, A., & Sharman, V. (2019). “It is not the same”: Relationships

and dementia. *Educational Gerontology*, *45*(7), 454–468.

<https://doi.org/10.1080/03601277.2019.1656892>

Blandin, K., & Pepin, R. (2017). Dementia grief: A theoretical model of a unique grief

experience. *Dementia (London)*, *16*(1), 67–78.

<https://doi.org/10.1177/1471301215581081>

Boss, P. (2010). The trauma and complicated grief of ambiguous loss. *Pastoral*

*Psychology*, *59*(2), 137–145. <https://doi.org/10.1007/s11089-009-0264-0>

- Boss, P., & Yeats, J. R. (2014). Ambiguous loss: A complicated type of grief when loved ones disappear. *Bereavement Care, 33*(2), 63–69.  
<https://doi.org/10.1080/02682621.2014.933573>
- Celdran, M., Villar, F., & Triado, C. (2012). When grandparents have dementia: Effects on their grandchildren's family relationships. *Journal of Family Issues, 33*(9), 1218–1239. <https://doi.org/10.1177/0192513X12443051>
- Centre for Clinical Interventions. (n.d.). *Fun activities catalogue*.  
<https://www.cci.health.wa.gov.au/-/media/CCI/Mental-Health-Professionals/Depression/Depression---Information-Sheets/Depression-Information-Sheet---06---Fun-Activities-Catalogue.pdf>
- Chan, D., Livingston, G., Jones, L., & Sampson, E. L. (2012). Grief reactions in dementia carers: A systematic review. *International Journal of Geriatric Psychiatry, 28*(1), 1–17. <https://doi.org/10.1002/gps.3795>
- Cheng, S.-T., Au, A., Losada, A., Thompson, L. W., & Gallagher-Thompson, D. (2019). Psychological interventions for dementia caregivers: What we have achieved, what we have learned. *Current Psychiatry Reports, 21*(7), 59.  
<https://doi.org/10.1007/s11920-019-1045-9>
- Cheng, S.-T., Fung, H. H., Chan, W. C., & Lam, L. C. W. (2016). Short-term effects of a gain-focused reappraisal intervention for dementia caregivers: A double-blind cluster-randomized controlled trial. *The American Journal of Geriatric Psychiatry, 24*(9), 740–750. <https://doi.org/10.1016/j.jagp.2016.04.012>

- Chirico, I., Ottoboni, G., Valente, M., & Chattat, R. (2021). Children and young people's experience of parental dementia: A systematic review. *International Journal of Geriatric Psychiatry, 36*(7), 975–992. <https://doi.org/10.1002/gps.5542>
- Chiu, Y.-C., Lee, Y.-N., Wang, P.-C., Chang, T.-H., Li, C.-L., Hsu, W.-C., & Lee, S.-H. (2014). Family caregivers' sleep disturbance and its associations with multilevel stressors when caring for patients with dementia. *Aging and Mental Health, 18*(1), 92–101. <https://doi.org/10.1080/13607863.2013.837141>
- Clark, M. C., Nicholas, J. M., Wassira, L. N., & Gutierrez, A. P. (2013). Psychosocial and biological indicators of depression in the caregiving population. *Biological Research for Nursing, 15*(1), 112–121. <https://doi.org/10.1177/1099800411414872>
- Commonwealth of Pennsylvania. (2022). *Caregiver support program*. Pennsylvania Department of Aging. <https://www.aging.pa.gov/aging-services/caregiver-support/Pages/default.aspx>
- Crespo, M., Lopez, J., & Zarit, S. H. (2005). Depression and anxiety in primary caregivers: A comparative study of caregivers of demented and nondemented older persons. *International Journal of Geriatric Psychiatry, 20*(6), 591–592. <https://doi.org/10.1002/gps.1321>
- Dassel, K. B., Carr, D. C., & Vitaliano, P. (2015). Does caring for a spouse with dementia accelerate cognitive decline? Findings from the health and retirement study. *The Gerontologist, 57*(2), 319–328. <https://doi.org/10.1093/geront/gnv148>
- Dening, T., & Sandilyan, M. B. (2015). Dementia: Definitions and types. *Nursing Standard (2014+), 29*(37), 37–42. <https://doi.org/10.7748/ns.29.37.37.e9405>

- Dobson, D., & Dobson, K. S. (2017). *Evidence-based practice of cognitive-behavioral therapy* (2nd ed.). Guilford Press.
- Eggenberger, E., Heimerl, K., & Bennett, M. I. (2012). Communication skills training in dementia care: A systematic review of effectiveness, training content, and didactic methods in different care settings. *International Psychogeriatrics*, 25(3), 345–358. <https://doi.org/10.1017/S1041610212001664>
- Fonareva, I., & Oken, B. S. (2014). Physiological and functional consequences of caregiving for relatives with dementia. *International Psychogeriatrics*, 26(5), 725–747. <https://doi.org/10.1017/S1041610214000039>
- Fossey, J., Charlesworth, G., Fowler, J.-A., Frangou, E., Pimm, T. J., Dent, J., Ryder, J., Robinson, A., Kahn, R., Aarsland, D., Pickett, J., & Ballard, C. (2021). Online education and cognitive behavior therapy improve dementia caregivers' mental health: A randomized trial. *Journal of the American Medical Directors Association*, 22(7), 1403–1409. <https://doi.org/10.1016/j.jamda.2020.10.009>
- Getting started with mindfulness. (2022, November 10). In *Mindful communications*. <https://www.mindful.org/meditation/mindfulness-getting-started/>
- Givens, J. L., Prigerson, H. G., Jones, R. N., & Mitchell, S. L. (2011). Mental health and exposure to patient distress among families of nursing home residents with advanced dementia. *Journal of Pain and Symptom Management*, 42(2), 183–191. <https://doi.org/10.1016/j.jpainsymman.2010.10.259>
- Goncalves-Pereira, M., Zarit, S. H., Cardoso, A. M., Alves da Silva, J., Papoila, A. L., & Mateos, R. (2020). A comparison of primary and secondary caregivers of persons

with dementia. *Psychology and Aging*, 35(1), 20–27.

<https://doi.org/10.1037/pag0000380>

Grafstrom, M., & Winblad, B. (1995). Family burden in the care of the demented and nondemented elderly — A longitudinal study. *Alzheimer's Disease and Associated Disorders*, 9(2), 78–86. <https://doi.org/10.1097/00002093-199509020-00004>

Hales, S. A., & Fossey, J. (2018). Caring for me and you: The co-production of a computerised cognitive behavioural therapy (cCBT) package for carers of people with dementia. *Aging & Mental Health*, 22(10), 1287–1294.

<https://doi.org/10.1080/13607863.2017.1348475>

Hall, M., & Sikes, P. (2018). How do young people 'do' family where there is a diagnosis of dementia? *Families, Relationships, and Societies*, 7(2), 207–225.

<https://doi.org/10.1332/204674316X14818999694306>

Harada, C. N., Natelson Love, M. C., & Triebel, K. (2013). Normal cognitive aging. *Clinics in Geriatric Medicine*, 29(4), 737–752.

<https://doi.org/10.1016/j.cger.2013.07.002>

Hofmann, S. G., Asnaani, A., Vonk, I. J. J., Sawyer, A. T., & Fang, A. (2012). The efficacy of cognitive behavioral therapy: A review of meta-analyses. *Cognitive Therapy and Research*, 36(5), 427–440. <https://doi.org/10.1007/s10608-012-9476-1>

Hopkinson, M. D., Reavell, J., Lane, D. A., & Mallikarjun, P. (2019). Cognitive behavioral therapy for depression, anxiety, and stress in caregivers of dementia

- patients: A systematic review and meta-analysis. *The Gerontologist*, 59(4), e343–e362. <https://doi.org/10.1093/geront/gnx217>
- Horrell, S. C. V. (2008). Effectiveness of cognitive-behavioral therapy with adult ethnic minority clients: A review. *Professional Psychology: Research and Practice*, 39(2), 160–168. <https://doi.org/10.1037/0735-7028.39.2.160>
- James, I. A., Reichelt, K., Moniz-Cook, E., & Lee, K. (2020). Challenging behaviour in dementia care: A novel framework for translating knowledge to practice. *The Cognitive Behaviour Therapist*, 13(e43), 1–13. <https://doi.org/10.1017/S1754470X20000434>
- Kosminsky, P. (2017). CBT for grief: Clearing cognitive obstacles to healing from loss. *Journal of Rational-Emotive & Cognitive-Behavior Therapy*, 35(1), 26–37. <https://doi.org/10.1007/s10942-016-0241-3>
- Koyama, A., Matsushita, M., Hashimoto, M., Fujise, N., Ishikawa, T., Tanaka, H., Hatada, Y., Miyagawa, Y., Hotta, M., & Ikeda, M. (2017). Mental health among younger and older caregivers of dementia patients. *Psychogeriatrics*, 17(2), 108–114. <https://doi.org/10.1111/psyg.12200>
- Lieberman, M. A., & Fisher, L. (1999). The impact of a parent's dementia on adult offspring and their spouses: The contribution of family characteristics. *Journal of Mental Health and Aging*, 5(3), 207–222.
- Lindgren, C. L., Connelly, C. T., & Gaspar, H. L. (1999). Grief in spouse and children caregivers of dementia patients. *Western Journal of Nursing Research*, 21(4), 521–537. <https://doi.org/10.1177/01939459922044018>



- Losada, A., Marquez-Gonzalez, M., Knight, B. G., Yanguas, J., Sayegh, P., & Romero-Moreno, R. (2010). Psychosocial factors and caregivers' distress: Effects of familism and dysfunctional thoughts. *Aging & Mental Health, 14*(2), 193–202. <https://doi.org/10.1080/13607860903167838>
- Losada, A., Marquez-Gonzalez, M., & Romero-Moreno, R. (2011). Mechanisms of action of a psychological intervention for dementia caregivers: Effects of behavioral activation and modification of dysfunctional thoughts. *International Journal of Geriatric Psychiatry, 26*(11), 1119–1127. <https://doi.org/10.1002/gps.2648>
- Markowitz, J. C., Spielman, L. A., Sullivan, M., & Fishman, B. (2000). An exploratory study of ethnicity and psychotherapy outcome among HIV-positive patients with depressive symptoms. *Journal of Psychotherapy Practice and Research, 9*(4), 226–231. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3330614/>
- Marquez-Gonzalez, M., Losada, A., Izal, M., Perez-Rojo, G., & Montorio, I. (2007). Modification of dysfunctional thoughts about caregiving in dementia family caregivers: Description and outcomes of an intervention programme. *Aging & Mental Health, 11*(6), 616–625. <https://doi.org/10.1080/13607860701368455>
- Mather, M., & Scommegna, P. (2020, May 28). *The demography of dementia and dementia caregiving* (No. 40). Population Reference Bureau. <https://www.prb.org/resources/the-demography-of-dementia-and-dementia-caregiving/>

- Mather, M., Scommegna, P., & Kilduff, L. (2019, July 15). *Aging in the United States* [Fact Sheet]. Population Reference Bureau. <https://www.prb.org/resources/fact-sheet-aging-in-the-united-states/>
- Meichsner, F., Kohler, S., & Wilz, G. (2019). Moving through predeath grief: Psychological support for family caregivers of people with dementia. *Dementia, 18*(7–8), 2474–2493. <https://doi.org/10.1177/1471301217748504>
- Meichsner, F., Schinkothe, D., & Wilz, G. (2016). Managing loss and change: Grief interventions for dementia caregivers in a CBT-based trial. *American Journal of Alzheimer's Disease and Other Dementias, 31*(3), 231–240. <https://doi.org/10.1177/1533317515602085>
- Meichsner, F., & Wilz, G. (2018). Dementia caregivers' coping with pre-death grief: Effects of a CBT-based intervention. *Aging & Mental Health, 22*(2), 218–225. <https://doi.org/10.1080/13607863.2016.1247428>
- Melemis, S. M. (2021, May 31). *CBT worksheet – Cognitive therapy thought record*. I Want to Change My Life. <https://www.iwanttochangemylife.org/tools/cbt-worksheet-thought-record.htm>
- Miron, A. M., Thompson, A. E., Bagley, A., Anderson, J., Melotik, E., & Rowley, S. (2019). Fear of incompetence in intergenerational relationships with a family member with dementia. *Journal of Intergenerational Relationships, 17*(4), 449–467. <https://doi.org/10.1080/15350770.2019.1575783>
- Montorio, I., Losada, A., Izal, M., & Marquez, M. (2009). Dysfunctional thoughts about caregiving questionnaire: Psychometric properties of a new measure.

*International Psychogeriatrics*, 21(5), 913–921.

<https://doi.org/10.1017/S1041610209990366>

Nam, I. (2016). Financial difficulty effects on depressive symptoms among dementia patient caregivers. *Community Mental Health Journal*, 52(8), 1093–1097.

<https://doi.org/10.1007/s10597-016-0033-3>

National Alliance for Caregiving & American Association of Retired Persons. (1997, June). *Family caregiving in the U.S.: Findings from a national survey*.

[https://assets.aarp.org/rgcenter/il/caregiving\\_97.pdf](https://assets.aarp.org/rgcenter/il/caregiving_97.pdf)

National Institute on Aging. (2019). *Caring for a person with Alzheimer's disease: Your easy-to-use guide from the National Institute on Aging*.

[https://order.nia.nih.gov/sites/default/files/2019-03/Caring\\_for\\_a\\_person\\_with\\_AD\\_508\\_0.pdf](https://order.nia.nih.gov/sites/default/files/2019-03/Caring_for_a_person_with_AD_508_0.pdf)

O'Sullivan, M., Brennan, S., Lawlor, B. A., Hannigan, C., Robertson, I. H., & Pertl, M. M. (2019). Cognitive functioning among cognitively intact dementia caregivers compared to matched self-selected and population controls. *Aging & Mental Health*, 23(5), 566–573. <https://doi.org/10.1080/13607863.2018.1428937>

Ory, M. G., Hoffman, R. R., Yee, J. L., Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *The Gerontologist*, 39(2), 177–185.

<https://doi.org/10.1093/geront/39.2.177>

Ory, M. G., Yee, J. L., Tennstedt, S. L., & Schulz, R. (2000). The extent and impact of dementia care: Unique challenges experienced by family caregivers. In R. Schulz

- (Ed.), *Handbook on dementia caregiving: Evidence-based interventions for family caregivers* (pp. 1–32). Springer Publishing Company.
- Pantalone, D. W., Iwamasa, G. Y., & Martell, C. R. (2010). Cognitive-behavioral therapy with diverse populations. In K.S. Dobson (Ed.), *Handbook of cognitive-behavioral therapies* (pp. 445–464). Guilford Press.
- Perrotta, G. (2020). General overview of “human dementia diseases”: Definitions, classifications, neurobiological profiles and clinical treatments. *Gerontology & Geriatrics Studies*, 6(1), 565–572. <https://doi.org/10.31031/GGS.2020.06.000626>
- Pinquart, M., & Sorensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging*, 18(2), 250–267. <https://doi.org/10.1037/0882-7974.18.2.250>
- Pinquart, M., & Sorensen, S. (2007). Correlates of physical health of informal caregivers: A meta-analysis. *Journal of Gerontology: Psychological Sciences*, 62B(2), 126–137. <https://doi.org/10.1093/geronb/62.2.p126>
- Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry*, 12(3), 240–249. <https://doi.org/10.1097/00019442-200405000-00002>
- Schulz, R., O’Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *The Gerontologist*, 35(6), 771–791. <https://doi.org/10.1093/geront/35.6.771>
- Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *The American Journal of Nursing*, 108(9), 23–27. <https://doi.org/10.1097/01.NAJ.0000336406.45248.4c>

- Shaik, S. S., & Varma, A. R. (2012). Differentiating the dementias: A neurological approach. *Progress in Neurology and Psychiatry, 16*(1), 11–18.  
<https://doi.org/10.1002/pnp.224>
- Sutton, J. (2021, December 20). *7 stress-relief breathing exercises for calming your mind*. Positivepsychology.com. <https://positivepsychology.com/breathing-exercises-for-stress-relief/>
- Sutton, J. (2022, December 14). *How to do activity scheduling: 6 templates & worksheets*. Positivepsychology.com. <https://positivepsychology.com/activity-scheduling-worksheets/#tips>
- Svanberg, E., Spector, A., & Stott J. (2011). The impact of young onset dementia on the family: A literature review. *International Psychogeriatrics, 23*(3), 356–371.  
<https://doi.org/10.1017/S1041610210001353>
- Teeple, R. C., Caplan, J. P., & Stern, T. A. (2009). Visual hallucinations: Differential diagnosis and treatment. *Primary Care Companion to the Journal of Clinical Psychiatry, 11*(1), 26–32. <https://doi.org/10.4088/pcc.08r00673>
- Therapist Aid. (2014, August 3). *How to do progressive muscle relaxation* [Video]. YouTube. <https://youtu.be/1nZEdqcGVzo>
- Thoma, N., Pilecki, B., & McKay, D. (2015). Contemporary cognitive behavior therapy: A review of theory, history, and evidence. *Psychodynamic Psychiatry, 43*(3), 423–462. <https://doi.org/10.1521/pdps.2015.43.3.423>
- Topfer, N. F., Sittler, M. C., Lechner-Meichsner, F., Theurer, C., & Wilz, G. (2021). Long-term effects of a telephone-based cognitive-behavioral intervention for family caregivers of people with dementia: Findings at 3-year follow-up. *Journal*

*of Consulting and Clinical Psychology*, 89(4), 341–349.

<https://doi.org/10.1037/ccp0000640>

University of Houston-Clear Lake. (2022, November 10). *Visualization and guided imagery*. <https://www.uhcl.edu/counseling-services/resources/visualization>

Van Wijngaarden, E., Van der Wedden, H., Henning, Z., Komen, R., & The, A.-M.

(2018). Entangled in uncertainty: The experience of living with dementia from the perspective of family caregivers. *PloS ONE*, 13(6), 1–21.

<https://doi.org/10.1371/journal.pone.0198034>

Verreault, P., Turcotte, V., Ouellet, M.-C., Robichaud, L.-A., & Hudon, C. (2021).

Efficacy of cognitive-behavioural therapy interventions on reducing burden for caregivers of older adults with a neurocognitive disorder: A systematic review and meta-analysis. *Cognitive Behaviour Therapy*, 50(1), 19–46.

<https://doi.org/10.1080/16506073.2020.1819867>

Vitaliano, P. P., Zhang, J., & Scanlan, J. M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, 129(6), 946–972.

<https://doi.org/10.1037/0033-2909.129.6.946>

Weisman de Mamani, A., Weintraub, M. J., Maura, J., Martinez de Andino, A., &

Brown, C. A. (2018). Stigma, expressed emotion, and quality of life in caregivers of individuals with dementia. *Family Process*, 57(3), 694–706.

<https://doi.org/10.1111/famp.12325>

Wilz, G., Reder, M., Meichsner, F., & Soellner, R. (2018). The Tele.TanDem

intervention: Telephone-based CBT for family caregivers of people with

dementia. *The Gerontologist*, 58(2), e118–e129.

<https://doi.org/10.1093/geront/gnx183>

Wilz, G., & Soellner, R. (2016). Evaluation of a short-term telephone-based cognitive behavioral intervention for dementia family caregivers. *Clinical Gerontologist*, 39(1), 25–47. <https://doi.org/10.1080/07317115.2015.1101631>

World Health Organization (2021, September 2). *Dementia*. <https://www.who.int/news-room/fact-sheets/detail/dementia>

Yorulmaz, E., & Dirik, G. (2021). Dementia caregivers and cognitive behavioural therapy: A systematic review. *Current Approaches in Psychiatry*, 13(2), 170–191. <https://doi.org/10.18863/pgy.732086>

Youell, J., Callaghan, J. E. M., & Buchanan, K. (2016). ‘I don’t know if you want to know this’: Carers’ understandings of intimacy in long-term relationships when one partner has dementia. *Ageing & Society*, 36(5), 946–967. <https://doi.org/10.1017/S0144686X15000045>

**APPENDIX A**

**THE DEMENTIA GRIEF MODEL (BLANDIN & PEPIN, 2017)**



## Appendix A

### The Dementia Grief Model (Blandin & Pepin, 2017)

| Stage      | Psychological State  | Dynamic Mechanism   |
|------------|--|---|
| Separation | Significant losses separate the family from the person with dementia                                   | Acknowledgement of loss   |
|            | Losses are compounded, meaning they become more frequent and more expansive as the dementia progresses | Acknowledgement of loss occurs when families recognize and process the losses they experience due to dementia   |
|            | Early losses include memory, communication, and engagement   | Acknowledgement of loss may be inhibited if families resist, deny, or fail to recognize the losses              |
|            | In the later stages, losses may include abilities to drive, cook, and dress                            | Families may not have enough time or energy to process the losses if they occur within a short amount of time   |
| Liminality | Period in-between a previous loss and an anticipated loss  | Tolerating difficult feelings   |
|            | Marked by ambiguity and uncertainty, as losses fluctuate and are unpredictable                         | Families acknowledge and process feelings such as sadness, anger, and helplessness                              |
|            | Gradual loss of the person with dementia before physical death   | Hindered if families avoid or suppress their painful feelings   |
|            | Prolonged due to long prognosis of dementia  | Avoidance of feelings manifest in behaviors such as unhealthy distraction, substance abuse, and anger outbursts |

| Stage        | Psychological State  | Dynamic Mechanism  |
|--------------|--|--|
| Re-emergence | <p data-bbox="565 285 1019 390">Families acknowledge, understand, and accept their losses and current circumstances</p> <p data-bbox="565 432 1019 495">Marked by feelings of closure and stability</p> <p data-bbox="565 537 1019 642">Results from tolerating and confronting painful emotions in the Liminality stage</p> <p data-bbox="565 684 1019 789">A temporary feeling of resolution before it cycles back to the Separation stage</p> | <p data-bbox="1045 285 1192 317">Adaptation</p> <p data-bbox="1045 359 1419 495">Families enact new behaviors that incorporate the loss into their lives</p> <p data-bbox="1045 537 1419 789">For example, assume new responsibility for the person with dementia or implement new ways of communicating based on the loss they have experienced</p> |

**APPENDIX B**  
**UNHELPFUL THOUGHTS IN CAREGIVERS**

## **Appendix B**

### **Unhelpful Thoughts in Caregivers**

Researchers developed a questionnaire of common unhelpful thoughts among family caregivers of individuals with dementia (Montorio et al., 2009). They found that many caregivers believe that they have sole responsibility for their loved one and that they should sacrifice their own needs and well-being to care for them. Also, many caregivers have perfectionistic tendencies and high expectations for themselves. In their study, the researchers found that individuals who had high levels of unhelpful thoughts related to caregiving had lower well-being (Montorio et al., 2009). Below are a few examples of these unhelpful thoughts that caregivers may experience (Montorio et al., 2009):

- Caregivers should avoid talking about their problems with others because others have their own lives and do not need to be bothered with more problems.
- When a person takes care of a frail/sick relative, he/she/they should set aside his/her/their interests and dedicate himself/herself completely to the care of the frail/sick relative.
- A caregiver should only seek help from others or find other alternatives when the caregiving situation is at its worst or when he/she/they can no longer handle it.
- It is selfish for a caregiver to dedicate time to himself/herself when a relative is frail/sick and needs care.
- It is logical for caregivers to give up their own needs, setting aside their own life satisfaction, in favor of their relative's needs.
- A good caregiver should never get mad or lose control with the person that is being cared for.

- If a caregiver has feelings of embarrassment and rejection toward his/her/their relative, it's because the caregiver is failing in some way with his/her/their caregiving duties.
- Good caregivers should remain happy and in good spirits all day long to deal adequately with the daily tasks of caregiving.
- To become a good caregiver would mean not making mistakes when taking care of a frail/sick relative.

What cognitive distortions do you notice among these statements? All-or-nothing thinking? "Should" statements? Labeling? Overgeneralization?

Take some time to reflect on which of these statements you identify with, or other unhelpful beliefs or assumptions you have about yourself and your role as a caregiver. How do these beliefs or thoughts make you feel? How do they affect your behaviors? Where do these thoughts come from—cultural views, family values, or other factors? Are these thoughts helpful?

**APPENDIX C**  
**BEHAVIORAL ACTIVATION STEPS**

## Appendix C

### Behavioral Activation Steps

#### Step 1: Reflect on Your Current Activity Levels

- What does my daily schedule currently look like?
- What barriers stand in my way of doing activities I enjoy and practicing self-care?
- How can I overcome these barriers?

#### Step 2: Identify Activities

- Write down a list of activities you enjoy and activities that give you a sense of accomplishment.
- Examples include watching a movie, going to the gym, reading a book, listening to music, sitting in the sun, gardening, talking with friends, working on your car, praying, cooking, thinking about happy memories, going for a walk, or trying something new.
- If you need ideas, the Centre for Clinical Interventions (n.d.) provides an extensive list of ideas for pleasurable activities:

<https://www.cci.health.wa.gov.au/-/media/CCI/Mental-Health-Professionals/Depression/Depression---Information-Sheets/Depression-Information-Sheet---06---Fun-Activities-Catalogue.pdf>

#### Step 3: Schedule Activities

- Using the worksheet in Figure C1, try to plan pleasurable activities throughout the week.

- Because caregiving can be demanding and time-consuming, it may be difficult for you to find the time for pleasurable activities. It’s important to start small. You may need to try activities that can be done in a short amount of time or while you are supervising your loved one.
- You could start with one positive activity per day and then increase to multiple times per day.
- Remember, it’s important to take breaks.

**Step 4: Reflect on the Outcome**

- After trying the schedule for a week, evaluate the outcome.
- What was easy? What was difficult? Did you notice improved well-being?  
How can you adjust for next week to overcome any obstacles you encountered?

**Figure C1**

*Behavioral Activation Schedule (Beck, 2011; Sutton, 2022)*

| <b>Day of the Week</b> | <b>Activity</b><br><i>Write the pleasurable or masterful activity you plan to complete</i> | <b>Scheduled Time</b><br><i>Write what time you plan to complete the activity</i> | <b>Outcome</b><br><i>Write how you felt after doing the activity, or what stopped you from completing the activity that day</i> |
|------------------------|--|---|---|
| <b>Sunday</b>          |  |   |   |



|                  |  |  |  |
|------------------|--|--|--|
| <b>Monday</b>    |  |  |  |
| <b>Tuesday</b>   |  |  |  |
| <b>Wednesday</b> |  |  |  |
| <b>Thursday</b>  |  |  |  |
| <b>Friday</b>    |  |  |  |
| <b>Saturday</b>  |  |  |  |

**APPENDIX D**  
**RESPIRE CARE**

## **Appendix D**

### **Respite Care**

Families may benefit from respite care, a short time of relief in which caregivers receive a break while the person with dementia continues to receive care (Alzheimer's Association, 2007). Respite services can occur at home or in the community, be provided by paid individuals or volunteers, or last for a short part of the day or several days. Respite care allows caregivers to complete personal tasks, spend time with family and friends, or simply relax. It also benefits the individual with dementia by allowing them to connect with others in the community and participate in activities outside of the home (Alzheimer's Association, 2007). The Alzheimer's Association (2007) identifies different options for respite services:

➤ In-home respite care:

- Professionals may come to the home to assist the individual with completing activities of daily living or provide medical care.
- This type of respite care may also include housekeeping services.
- Additionally, paid professionals or volunteers may visit the home to provide companionship and spend time with the individual with dementia to increase social interaction and provide relief for the caregiver (Alzheimer's Association, 2007).

➤ Adult day centers:

- Individuals with dementia may spend the day at an adult day center to receive supervised care.

- Adult day centers usually include activities (e.g., games, movies, field trips) and support groups for the individuals with dementia.
  - These centers may also provide nursing, personal care, and nutrition services.
  - Staff varies according to the program, but usually includes medical staff and recreational therapists.
  - This option can be especially useful for family caregivers who work during the day (Alzheimer's Association, 2007).
- Residential care
- Residential services are similar to adult day centers but provide long-term care, such as overnight or for a few days.
  - Residential centers likely require a reservation in advance.
  - This type of respite care may be useful for caregivers who need relief for an extended period of time (Alzheimer's Association, 2007).
- Informal respite care
- This type of respite care is provided by family, friends, or neighbors who offer help, rather than professional services.
  - Caregivers may coordinate with loved ones or friends to schedule times when they can offer assistance or provide relief (Alzheimer's Association, 2007).

**APPENDIX E**  
**RELAXATION TECHNIQUES**

## Appendix E

### Relaxation Techniques

#### Progressive Muscle Relaxation

- Progressive muscle relaxation is a technique that is used to reduce anxiety and muscle tension by tensing and relaxing parts of your body.
- Here is a link to a video that will guide you through the exercise:  
<https://youtu.be/1nZEdqcGVzo> (Therapist Aid, 2014)

#### Breathing Exercises

- Breathing exercises can also be used to reduce feelings of anxiety, stress, and anger.
- One breathing exercise is the 4-7-8 breathing technique (Sutton, 2021):
  - Inhale with your mouth closed to a count of 4.
  - Hold to a count of 7.
  - Exhale to a count of 8 with pursed lips and a “whooshing” sound.
  - Repeat the cycle up to 4 times, if comfortable.
- Another breathing exercise is box breathing (Sutton, 2021):
  - Inhale for 4 seconds.
  - Hold for 4 seconds.
  - Exhale for 4 seconds.
  - Hold for 4 seconds.
  - Repeat.

**Mindfulness Meditation**

- Mindfulness meditation has been found to improve mental and physical health, such as by reducing stress, anxiety, depression, pain, and fatigue (American Psychological Association, 2019).
- It includes two components: attention and acceptance (American Psychological Association, 2019).
  - Attention means awareness of the present moment (e.g., your thoughts, feelings, and physical sensations).
  - Acceptance means observing the moment without judgment, and letting your thoughts go without responding to them.
- There are many online resources for learning and practicing mindfulness. Check out the following website on how to get started with mindfulness:  
<https://www.mindful.org/meditation/mindfulness-getting-started/> (“Getting Started with Mindfulness,” 2022)

**Guided Imagery or Visualization**

- Guided imagery or visualization is another type of meditation that can be used to promote relaxation.
- The following link has audio and video resources for guided imagery:  
<https://www.uhcl.edu/counseling-services/resources/visualization#video>  
(“Visualization and Guided Imagery,” 2022)

**APPENDIX F**  
**MANAGING CHALLENGING BEHAVIORS**



## **Appendix F**

### **Managing Challenging Behaviors**

As a caregiver for someone with dementia, you may deal with challenging behaviors and personality changes, such as increased agitation and aggression, low frustration tolerance, impulsivity (e.g., doing things without thinking, lack of self-control), depression and anxiety, hallucinations and delusions, paranoia, and pacing and wandering (American Psychiatric Association, 2022; James et al., 2020; National Institute on Aging, 2019). Below are skills and strategies for managing and coping with difficult behaviors:

- Identify triggers to your loved one's difficult behaviors (James et al., 2020; National Institute on Aging, 2019).
  - It can be helpful to keep track of situations that occur prior to your loved one's difficult behaviors and look for patterns.
  - For example, your loved one may tend to become upset or agitated at certain times of the day or when they are asked to complete certain tasks like bathing or dressing.
  - By keeping track of triggers and situations, you can become more observant and prepared for difficult behaviors that may occur.
  - Try to create a daily, structured routine for your loved one so they know what to expect. This may minimize the amount of unpredictable situations that may lead to challenging behaviors.

- Utilize effective communication skills to both prevent challenging behaviors and decrease escalation when they do occur (Eggenberger et al., 2012; James et al., 2020; National Institute on Aging, 2019).
  - Use simple sentences and provide one-step instructions.
  - Ask closed-ended questions (such as yes/no questions or provide choices) instead of open-ended questions.
  - Avoid arguing or trying to reason with your loved one if they are expressing delusions, hallucinations, or paranoia.
  - Use non-threatening body language and maintain eye contact with your loved one when speaking with them.
  - Avoid using infantilizing speech.
- When a challenging behavior occurs, such as agitation:
  - Continue to utilize effective communication skills and avoid confrontation with your loved one (Eggenberger, 2012; National Institute on Aging, 2019).
  - Show empathy and validate your loved one's emotions. For example, "I hear you are worried" or "I understand you are feeling angry" (Eggenberger et al., 2012; National Institute on Aging, 2019).
  - Model calmness and emotional regulation to decrease escalation. Utilize relaxation techniques such as deep breathing or take a step away from your loved one to reduce your own frustration (James et al., 2020; National Institute on Aging, 2019).

- Try to change the environment or provide a distraction, such as moving to a different room, playing music, or asking your loved one to engage in a task they enjoy (James et al., 2020; National Institute on Aging, 2019).
- If your loved one is becoming aggressive, try your best to keep them safe from harming themselves, such as by moving harmful objects from within their reach. Keep yourself and others safe by giving the person with dementia space, if possible (National Institute on Aging, 2019).
- After the challenging behavior has ended, use calming strategies such as moving to a different environment or engaging in a task they enjoy. Your loved one may be at higher risk to be re-triggered, so avoid asking them to do demanding tasks immediately following the behavior (James et al., 2020).

**APPENDIX G**  
**ADDITIONAL RESOURCES**

## Appendix G

### Additional Resources

#### Dementia Organizations

- Alzheimer's Association: <https://www.alz.org/>
- Find your local chapter for resources in your area:  
[https://www.alz.org/local\\_resources/find\\_your\\_local\\_chapter](https://www.alz.org/local_resources/find_your_local_chapter)
- Alzheimer's Foundation of America: <https://alzfdn.org/>
- Dementia Society of America: <https://www.dementiasociety.org/>

#### Helplines

- Alzheimer's Foundation of America (AFA) Helpline:  
<https://alzfdn.org/afahelpline/>
- Accessible by telephone, web chat, and text message
- Staffed by licensed social workers 9am – 9pm ET, seven days a week to answer questions and assist with caring for an individual with dementia
- Alzheimer's Association 24/7 Helpline:  
[https://www.alz.org/norcal/helping\\_you/24\\_7\\_helpline](https://www.alz.org/norcal/helping_you/24_7_helpline)

#### Support Groups

- Weekly telephone support groups: <https://alzfdn.org/caregiving-resources/support-groups/>
- Online and telephone support groups:  
[https://www.alz.org/norcal/helping\\_you/support\\_groups](https://www.alz.org/norcal/helping_you/support_groups)

- Virtual caregiver support groups:

<https://www.hopehealthco.org/services/support-groups/caregiver-support-group/>

### **Psychotherapy**

- If you are in need of one-on-one or family therapy or counseling to help you manage mental health difficulties, you can utilize Psychology Today to search for clinicians in your area who fit your needs:

<https://www.psychologytoday.com/us/therapists>

### **Respite Care**

- Use the Alzheimer's Association community resource finder to locate local in-home care, community services, and residential options:

<https://www.communityresourcefinder.org/>

- Find your local Area Agency on Aging (AAA) website to search for respite care in your area:

[https://www.payingforseniorcare.com/find\\_aging\\_agencies\\_adrc\\_aaa](https://www.payingforseniorcare.com/find_aging_agencies_adrc_aaa)

### **Financial Resources**

- Information on the Alzheimer's Caregiver Support Act:

[https://alzimpact.org/caregiver\\_support\\_act](https://alzimpact.org/caregiver_support_act)

- Information on eligibility and how to apply to the Pennsylvania Caregiver Support Program: [https://www.aging.pa.gov/aging-services/caregiver-](https://www.aging.pa.gov/aging-services/caregiver-support/pages/default.aspx?fbclid=IwAR2mOfb0CXk6Lfb949EGmt7CsuxZvsf)

[support/pages/default.aspx?fbclid=IwAR2mOfb0CXk6Lfb949EGmt7CsuxZvsf](https://www.aging.pa.gov/aging-services/caregiver-support/pages/default.aspx?fbclid=IwAR2mOfb0CXk6Lfb949EGmt7CsuxZvsf)

[YO6mMk0kU80xNk05kIETrNi-CJCM](https://www.aging.pa.gov/aging-services/caregiver-support/pages/default.aspx?fbclid=IwAR2mOfb0CXk6Lfb949EGmt7CsuxZvsf)

**Phone Apps**

- Calm – Mindfulness meditation, relaxation techniques, and stress relief (free version or subscription)
- MoodTools – Free app with thought records, mood monitoring, and activity tracking
- What's Up? – Free app based on CBT that includes journaling, coping strategies, and mental health education

**APPENDIX H**  
**RERB APPROVAL FORM**



**IMMACULATA UNIVERSITY RESEARCH ETHICS REVIEW BOARD  
REQUEST FOR PROTOCOL REVIEW--REVIEWER'S COMMENTS FORM  
(R1297)**

**Name of Researcher:** Margaret Czapski

**Project Title:** Coping with Dementia: A Resource for Families and Loved Ones

**Reviewer's Comments**

Your proposal is **Exempt**. It meets the requirements set forth in 45 CFR, 46.110(b) (1) sections # 5 and 7. You may begin your research or collect your data.

**Reviewer's Recommendations:**

Exempt  
 Expedited  
 Full Review

Approved  
 Conditionally Approve  
 Do Not Approve

*Marcia Parris*

June 8, 2022

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Marcia Parris, Ed.D.  
Chair, Research Ethics Review Board

DATE