Development of a Caregiver Education Support Tool for Family Caregivers of Older Adults with Dementia

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Abstract

For every person diagnosed with dementia, four family members are affected and burdened with providing care. Providing familial care is associated with greater psychological, social, and emotional burden on the caregiver. Caregivers are not provided with adequate education to support successful caregiving and aging in place. This capstone project developed and piloted a caregiver education support tool to simplify the process of finding caregiver education. Five caregivers participated in interviews to guide the development of the support tool, next completed the Likert questionnaire, and tested the caregiver education support tool. Four themes were identified: (1) burden, (2) loss, (3) unmet caregiver education needs, and (4) pendulum of emotions. Qualitative themes were then compared with the Likert questionnaire. This capstone project aimed to simplify identifying appropriate caregiver education and decrease caregiver burden.

Key words: Dementia, Alzheimer’s Disease, caregiving, caregiver burden, evidence based, education, occupational therapy
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Chapter 1: Introduction

Home to one of the highest prevalence’s of dementia in the country, Connecticut’s economy and health care industry has been significantly impacted by the number of familial caregivers providing care for people with dementia. Caregivers are unaware and uneducated regarding the logistics associated with supporting someone with dementia to age in place (Ellen at al., 2016). In addition to the lack of education, caring for someone with dementia has significant negative impacts on the caregivers. Caregiving for person with dementia is often associated with depression, financial strain, and caregivers are at high risk for developing psychiatric disorders without adequate tools and education (Ellen, et al., 2016). With the prevalence and cost for dementia rapidly increasing, caregiver education is being utilized as an innovative means for addressing challenging dementia related behaviors, improving engagement, quality of life, and decreasing caregiver burden (Hungerford, Jones, & Cleary, 2014).

Background and Significance

In 2018, there were more than 5 million Americans living with dementia; by 2050, this number is expected to increase to 16 million (Alzheimer’s Association, 2018). As the prevalence of dementia continues to rise, more informal or familial caregivers will be responsible for providing care to their loved ones with dementia in their home. Aging in place has become an increasingly more popular method of aging for older adults with dementia with over 95% of adults aged 75 years and older wish to remain in their home as long as possible (Benefield & Holtzclaw, 2014). Emphasizing this point further, Kaplan reported that the number of older adults, aged 85 and older living in institutions has decreased from 26% in the 1970’s to less than 14% in the 2000’s. (Kaplan, Andersen, Lehning, & Perry, 2015). With more people with
dementia (PWD) and their families choosing to age in place, more family members will be responsible for providing care. For every person diagnosed with dementia, four family members are affected and burdened with providing care (Ellen, et al., 2016). Providing informal care is associated with significant less cost than institutionalized care, however, familial caregiving generates greater psychological, social, and emotional burden on the caregiver. In addition, according to the Alzheimer’s Association, dementia care will cost the nation $259 billion in 2017, and is expected to rise as high as $1.1 trillion dollars by 2050. Connecticut, where this capstone student lives and works, has one of the highest incidences of dementia in the country, which will require significant changes to our current health care service and caregiver resources (Koller & Bynum, 2015).

Along with the economic implications of caring for a person with dementia, the caregiver can also experience challenges with the adult with dementia. Of the 5.5 million Americans living with dementia, up to 96% of them will experience agitation, behavioral, and sleep disturbances; sleep changes, negative dementia-related behaviors, and difficulties with activities of daily living (ADLs) are reported to be the primary cause of caregiver burnout and institutionalization (Eska, Gressel, Donath, Schwarzkopf, Lauterberg, & Holle, 2013; Lyketsos et al., 2012). Due to the frequency of agitation and aggression associated with dementia and the high occurrence of caregiver burnout, many older adults with dementia are institutionalized, despite client and family preferences (Kelsey, Laditka, & Laditka, 2010).

As the prevalence of dementia continues to rise, more family members will be responsible for providing care; in 2018 there were 44 million informal or familial caregivers providing 37 billion hours of unpaid caregiving (Alzheimer’s Association, 2018). The economic valuation of providing informal care to older adults with dementia is estimated to be around
$217.7 billion and these costs are expected to rise (National Alliance for Caregiving, 2018). The monetary value of informal caregivers is significant and frequently underappreciated, and without these caregivers, people with dementia would experience poorer quality of life and higher likelihood of institutionalization (Edwards, 2015; Lilly, Robinson, Holtzman, Bottorff, 2012). According to the Alzheimer’s Association (2018), there are three primary reasons informal caregivers provide care for a loved one with dementia; the desire to keep the family member at home, the geographical proximity to the PWD and the caregiver’s perceived obligation as spouse or partner.

Caregivers often dedicate countless hours and efforts to care for the person with dementia, often at the expense of their own health and well-being. Family caregivers are often called the invisible second patient, as they are critical to the well-being of the person with dementia, however, they often experience significant burden, psychosocial issues, depression, isolation, financial strains, and poor physical health (Brodaty & Donkin, 2009). Tremont (2011) describes how the prolonged stress caused by caregiver burden can often negatively impact immunologic and hormonal functioning, putting the caregiver at risk of illness and disease (Tremont, 2011). Additionally, over a four-year period, caregivers of PWD experienced a 63% increase premature death than non-caregivers (Norton, Smith, & Ostbye, et al., 2010).

Despite the research that indicates caregivers are at high risk for burden and illness without adequate education and support, caregivers report they are not receiving adequate proactive education (Mastel-Smith & Stanley-Hermanss, 2012). Caregivers most frequently receive education retroactively to a significant issue or challenge. According to a large national study conducted in 2015, caregivers receive information from several sources. Twenty-two percent of caregivers receive education from physicians, 11% from nurses, 20% from family and
friends, 11% from other health care professionals, and 53% from the internet (NAC & AARP, 2009). Although the majority of families would prefer to turn to their primary care physician to provide education, the information received is often insufficient due to the limited time spent with a physician, resulting in families using the internet as their primary source of education (Peterson, Hahn, Lee, Madison, & Atri, 2016).

Danzl et al., 2016 indicate that caregivers would prefer to receive education in person, however, caregivers report that they are challenged to find someone to care for the person with dementia when education is offered by these professionals through workshops. Caregivers find home visits, another common source of education, to be useful but they found this source inconsistently useful (Danzl et al., 2016). While the internet is the most easily accessible means of education, caregivers are unable to ask specific questions, they may not have access to the internet, and must determine the reliability of information (Mastel-Smith & Stanley-Hermanns, 2012). Caregivers that participated in an interview with Danzl et al., 2016, reported that written materials were the most useful method of education for the ability to refer back to the education as needed.

There is a discrepancy between common topics that caregivers want to be educated about and the education they are receiving. Danzl et al., (2016) identify behavior management, safety, and resistance to care, experience these challenges which have been identified as the most common reasons for institutionalization and caregiver burden (Danzl et al., 2016). However, caregivers are most frequently being educated on topics that are not identified as high priority such as equipment and medication management (Mastel-Smith & Stanley-Hermanns, 2012). In addition, caregivers experience significant challenges with environmental barriers, social isolation, and supports. There are many practical and environmental barriers, including a lack of
education impacting informal caregiver’s ability to keep their loved one at home. As a result of this inadequate education, caregivers experience significant challenges in supporting aging in place and can become overwhelmed by practical and logistical barriers, such as social isolation and poor supports. Minimizing such barriers can improve occupational performance and harmony between the caregiver and care receiver. Supported by occupational therapy education, training, and philosophy, as well as this capstone student’s work experience and the literature on caregiving, dementia, and adult learning occupational therapists are well-suited to be involved in caregiver education and serve as a resource for caregivers seeking education.

**Purpose and Objectives**

Connecting caregivers to evidence-based education programs suited to their experience and preferences will improve their knowledge of disease progression, environmental modifications, adaptive equipment, and community resources that will decrease caregiver burden, improve occupational balance, occupational engagement, and promote aging in place for people with dementia. The caregiver education support tool being developed in this capstone project will facilitate caregiver self-reflection to identify personal challenges based upon the five most common causes of institutionalization. The self-reflection activities will be followed by a questionnaire that will rate the caregivers level of agreement regarding caregiver education program price, method, format, and content. Together, the self-reflection activities and the questionnaire will lead to a recommendation for the most appropriate evidence-based caregiver education program or programs. The written format of the caregiver education support tool provides a unique educational opportunity for caregivers to review and re-read materials as needed. The caregiver education support tool will allow caregivers to self-reflect on their caregiving challenges and priorities in the areas of behavior management, activities of daily

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living difficulty, caregiver burden, occupational balance, and environmental safety. The questionnaire will confirm the caregiver’s most significant challenges, degree of caregiver burden, and identify caregiver preferences for format and logistics of a caregiver education program to ultimately lead to a program recommendation that will be useful and impactful. Many of the education programs included in the support tool were created by occupational therapists to provide a holistic approach to occupational wellness for caregivers.

Occupational therapists are in a unique position to understand caregiver education needs and make education recommendations due to their ability to analyze functional abilities, occupational performance, and environmental impacts on performance and quality of life. Occupational therapists can provide caregiver education specific to the enablers and barriers present in the natural environment of the home. Collaborating with the caregiver and people with dementia, an occupational therapist can provide individualized, client-centered care that would be effective in improving occupational performance and decreasing caregiver burden (Edwards, 2015). Occupational therapists can connect caregivers to evidence-based education programs that address a variety of topics including: environmental modifications, behavior modifications, minimizing caregiver burden, and activity adaptations to improve occupational performance of the person with dementia. In addition, occupational therapists can provide client-centered education and guidance on community resources and supports to decrease caregiver burden (Edwards, 2015). Many of the evidence-based caregiver education programs that will be included in the support tool, have involved occupational therapist’s due to their expertise on occupational performance.

The purpose of this capstone project is to create a caregiver education support tool that will result in a caregiver education program recommendation. The support tool will connect
caregivers to reliable, evidence-based education program or programs that will meet their needs and minimize the overwhelming process of finding suitable education programs. Caregiver education programs included in the support tool will all have research to support the efficacy of the program and will relate to multiple aspects of disease progression and physical and logistical barriers to aging in place, while addressing a caregiver’s psychosocial needs.

The overarching goal of the caregiver education support tool is to decrease caregiver burden, improve the effectiveness of their caregiving, and improve aging in place for people with dementia. The objectives of this capstone project are to understand the lived experiences of caregivers to connect them to the most appropriate evidence-based caregiver education programs. To accomplish this end goal, the support tool will provide caregivers the opportunity for self-reflection on their caregiving experiences based upon the five most common causes of institutionalization. This capstone project will result in a caregiver educations support tool that is comprised of self-reflective activities and a questionnaire. The results of these activities will recommend an evidence-based caregiver education program that will be most applicable to their caregiving experience, and thereby ultimately decreasing caregiver burden and improve the person with dementia’s ability to age in place.

Definition of Terms

There are several terms used throughout this project. The definitions of these terms are as followed:

**Informal caregiver:** an unpaid person, typically friend or family member, providing care for an older adult with dementia.

**Aging in place:** A term used to describe, “The ability to live in one’s own home and community safely, independently, and comfortably, regardless of age, income, or ability level”. (Centers for Disease Control and Prevention, 2009).
Caregiver burden: The distress experienced by dementia caregivers which includes objective aspects of care (time and physical aspects of providing care) and subjective aspects of caregiving (emotional reactions to caregiving).

Occupational balance: An individual’s perception of having adequate balance amongst physical, mental, and social occupations (Wagman et al., 2012). This includes a balance amongst leisure pursuits and required activities. When an individual does not have occupational balance, they experience occupational imbalance.

Occupational imbalance: An individual’s perception of having inadequate balance amongst occupations. Dementia caregivers often spend a significant amount of time resulting in less time to engage in other preferred occupations.

Evidence-based: A term used to indicate there is research to support the use of or efficacy of a caregiver education program.

Support tool: A support tool for the purpose of this capstone, is a written document that will facilitate caregivers to self-reflect on their caregiving experience and result in an evidence-based caregiver education program recommendation.

Chapter 2: Literature Review
In 2018, there were more than 5 million Americans living with dementia; by 2050, this number is expected to increase to 16 million (Alzheimer’s Association, 2018). As the prevalence
of dementia continues to rise, more informal or familial caregivers will be responsible for providing care to their loved ones. For every person diagnosed with dementia, four family members are affected and burdened with caregiving (Ellen, et al., 2016). Providing informal care is associated with a significantly lower cost than institutionalized care, however, caregivers are often unaware and under educated regarding the costs and logistics associated with supporting someone with dementia to age in place. Additionally, caring for someone with dementia has significant negative impacts, including depression, financial strain, and a high risk for developing psychiatric disorders (Ellen, et al., 2016).

According to the National Alliance for Caregiving (2018), approximately 43.5 million caregivers have provided unpaid care to an older adult. The economic valuation of providing informal care to older adults with dementia is estimated to be $217.7 billion, with costs expected to rise (National Alliance for Caregiving, 2018). With the prevalence of dementia and cost of dementia care rapidly increasing, caregiver education is being utilized as an innovative means for addressing challenging dementia-related behaviors, improving engagement, quality of life, and decreasing caregiver burden (Hungerford, Jones, & Cleary, 2014). Occupational therapists are in a unique position to support the caregiver in developing routines that promote occupational balance, and to provide individualized client centered caregiver education.

The purpose of this literature review is to explore the experience of caregiving, to identify the barriers to aging in place, and to inform the development of a caregiver education support tool to influence caregiver burden, promote occupational balance, and support caregivers’ ability to assist people with dementia’ to age in place by connecting the caregiver to evidence-based caregiver education programs.
Barriers to Aging in Place

In order to most effectively address this issue, the barriers to successful aging in place and reasons for institutionalization must be understood. Eska et al., (2013) followed 357 community-dwelling older adults with mild-moderate dementia for four years to identify predictors of institutionalization. The most common reasons identified were difficulties with activities of daily living (ADLs), the perception of caregiver burden, and negative dementia-related behaviors including agitation, aggression, and resistance to care. Of the caregivers identified in the study, Eska et al., (2013) concluded that interventions to reduce caregiver burden would significantly decrease institutionalization.

Expanding upon the knowledge of factors leading to institutionalization, Fauth, Femia, and Zarit (2016) conducted a quasi-experimental study to identify resistance to care during specific ADLs. Researchers analyzed data from 234 persons with dementia using a weekly behavior record for caregivers to document resistant behaviors during eating, bathing, and dressing and to rate how upsetting these behaviors were. Frequency of resistance to care and negative dementia-related behaviors correlated to negative caregiver outcomes, wellness, and quality of life (Fauth, Femia, & Zarit, 2016). Caregivers’ perceptions and outlook on caregiving significantly correlated to the outcome of the care receiver. Caregivers who were unable to tolerate these behaviors significantly increased the probability of institutionalization and burden.

Due to the high likelihood of institutionalization of persons with dementia and caregiver burden, Thoma-Lurken, Bleijevens, Lexis, Witte, and Hamers (2017) interviewed 43 informal caregivers to determine the practical barriers preventing successful aging in place. While caregivers were unable to identify the primary barrier to aging in place, they described several problem categories: decreased independence with ADLs, safety-related issues, isolation of the
caregiver and person with dementia, behavior problems, and lack of resources (Thoma-Lurken, Bleijevens, Lexis, Witte, & Hamers, 2017). These findings support the results of Eska et al., (2013) that increased difficulty with ADLs and negative dementia-related behaviors are among the most common barriers to aging in place. Caregivers identify difficulty managing behaviors, ADL dependence, and their own feelings of social isolation as significant challenges in supporting occupational engagement for care receivers.

**Unmet Burden of Care**

Caregivers often reach their burden threshold due to a series of unmet needs that actively inhibit their ability to support their loved one to age in place. A mixed methods study was conducted by Ducharme, Kergoat, Coulombe, Levesque, Antoine, and Pasquier, (2014) with 32 family caregivers to identify unmet support needs in Canada. Through outcome measures and qualitative interviews, researchers concluded that caregivers need more extensive knowledge of resources, proper caregiving instruction, and skills to manage caregiver burden and stress. The authors concluded that the majority of caregivers’ unmet needs related to psycho-educational needs rather than instrumental needs (Ducharme, Kergoat, Coulombe, Levesque, Antoine, & Pasquier, 2014). Psycho-educational needs involve social supports, resources, and education while instrumental needs describe logistical concerns such as adaptive equipment and modifications.

Caregivers are often undereducated, under supported, and underappreciated. The health care community often adds additional stress to caregivers by providing assistance retroactively, when the caregiver has reached their burden threshold. Familial caregivers are often not viewed as a valuable member of the healthcare team and are not given education regarding resources proactively. This notion is validated by another international study conducted by Lilly,
Robinson, Holtzman, Bottorff, (2012). The researchers interviewed 23 caregivers who reported disappointment that their commitment to care was being taken for granted by the health care community and the care recipient. In addition, Lilly, Robinson, Holtzman, & Bottorff, (2012), reported that caregivers are struggling to balance caregiving responsibilities with their need for occupational engagement. This poor recognition from health care practitioners and the inability to engage in personally meaningful occupations result in psychosocially overburdened caregivers.

Rodriguez-Perez et al., (2017) conducted a cross-sectional study with a large sample size of 86 familial caregivers in Spain. Quality of life dimensions were selected as the dependent variable while confounding variables were demographics, perceived burden of caregiver, and functional abilities of the care receiver. Researchers found that poor coping strategies correlated to poorer quality of life for caregivers and care receivers. Rodriguez-Perez et al., (2017) concluded that when caregivers were educated about caregiver burden, quality of life, and using adaptive coping strategies, caregivers demonstrated improvement in a number of quality of life factors.

Caregivers may turn to institutionalization as reprieve from the burden, however, studies indicate that some caregivers may experience increased feelings of burden, depression, and guilt associated with placement (Cheng, 2017). In a sample of over 3,000 caregivers, researchers completed descriptive analysis of 6 and 12-month post placement data (Gaugler, Mittelman, Hepburn, & Newcomer, 2009). Although these studies were conducted internationally, the findings are applicable to experiences of caregivers in the United States. The broader international sociopolitical influences described by Lilly et al., (2012) are similar to caregiver reports within the United States, that the health care system poorly provides preventative
resources and support services. Dizazzo-Miller, Samuel, Barnas, & Welker, (2014), concluded that with limited education and support, familial caregivers typically experience physical, psychological, socioemotional, financial struggles, and occupational imbalance

**Occupational Imbalance**

A sense of balance is a subjective state of being involving attitudes, goals, and perspective, influenced by the external environment (Backman, 2004). Occupational balance is believed to enhance well-being and quality of life. Caregivers often spend a substantial amount of time providing care and have limited time to engage in meaningful occupations, which creates imbalance and poor well-being. Occupational imbalance refers to a person’s perception of having an imbalance amongst physical, mental, and social occupations (Wagman et al., 2012). Edwards (2015) conducted a qualitative study to explore the experiences of 10 familial caregivers who reported a loss of identity and burden due to the time-consuming nature of caregiving and inability to engage in leisure, social, or work occupations. Many caregivers reported having to stop working due to the overwhelming demands of caregiving. The combination of high levels of stress and inability to engage in meaningful occupations left caregivers feeling a loss of identity, poor physical health, and financial and emotional strain (Edwards, 2015). The results of Edward’s (2015) study are echoed in Pitensberger’s (2006) critical review on balancing work and caregiving responsibilities. Pitensberger (2006) analyzed demographics, research, national statistics, and health care trends and determined that family members frequently reported their responsibilities impact their ability to perform at work; and many reported they resort to quitting work or retiring early to have more time to care for the person with dementia due to caregiving responsibilities (Pitensberger, 2006; National Alliance for Caregiving, 2015). According to Pitensberger (2007) and Edwards (2015), as the disease
progresses, a caregiver’s ability to engage in any other occupation decreases, resulting in occupational imbalance and burden.

The concept of occupational balance is deeply rooted in occupational therapy (OT) practice. According to Yazdani, Harb, Rassafiani, Nobakt, and Yazdani (2018), occupational therapists are uniquely qualified to address caregiver occupational balance due to their ability to analyze occupational participation, a person’s capabilities, and environmental influences on occupational performance.

**Occupational Therapy’s Role in Supporting Caregivers and Care Receivers**

Occupational therapy practitioners can often be the first health care provider to identify caregiver challenges and barriers to both the care receiver and the care receiver’s occupational performance. Evidence-based occupational therapy treatment is one of the most promising multi-component psychosocial interventions to both the caregiver and care receiver (Leven, Kaijen, de Swart, Rikkert, & Vernooji-Dassen, 2012). Occupational therapy practitioners provide individualized, client centered intervention that addresses the caregiver-care receiver dyad. Specifically, Community-based OT intervention has demonstrated the greatest rates of improvement in daily functioning for the person with dementia and has been shown to decrease caregiver burden (Yong & Price, 2014).

Occupational therapists can support occupational balance by addressing habits, roles, and routines for the person with dementia and their caregiver and are well qualified to provide individualized caregiver education that addresses personal and contextual factors. Yong and Price (2014) describe occupational therapist’s skills and knowledge in activity analysis, environmental adaptations, and modifications which can be used to support caregivers in developing, engaging in, and prioritizing daily occupations in a manner that will facilitate
occupational balance for the caregiver. Yong and Price (2014) conducted a meta-synthesis to identify the occupational needs of a dementia caregiver and the role of occupational therapy in minimizing caregiver burden and supporting aging in place. The researcher’s conclusions of this study describe the need for occupational therapists to collaborate and support the caregiver’s occupational engagement (Yong & Price, 2014). The researchers concluded that participating in a variety of meaningful occupations can improve caregivers’ wellness and decrease burden. In addition to addressing the caregiver’s occupational and educational needs, occupational therapists are experts in assessing and providing interventions to optimize occupational performance for persons with dementia. The use of occupation can also be helpful in addressing well-being, quality of life, and prolonging functional skills for the person with dementia.

Occupational therapists can design specific interventions for people with dementia that will promote occupational performance and participation. Kumar et al., (2014), trialed a novel occupational therapy intervention to address quality of life for older adults with dementia. The intervention consisted of relaxation, physical exercise, grooming, cognitive exercises, and meaningful leisure participation. Seventy-one participants were randomly assigned to the intervention and control group. Older adult participants in the intervention group demonstrated significantly improved quality of life scores and participants in the control group resulted increased depression scores and poorer quality of life outcomes (Kumar et al., 2014).

A systematic review by Smallfield & Heckenlaible (2017) sought to examine the effectiveness of occupational therapy intervention with persons with dementia. Of the 52 articles included in the review, eight articles addressed occupation-based interventions. Five of the eight articles reported statistically significant reduction in ADL dysfunction as a result of occupational therapy practitioners providing occupation-based intervention (Smallfield & Heckenlaible,
These results are significant to occupational therapy practitioners as ADL dysfunction is one of the common causes of caregiver burden and institutionalization.

Occupational therapy intervention can assist with addressing caregiver and care receiver needs, occupational balance, and recommend activities to improve the persons with dementia’s quality of life and reduce negative dementia-related behaviors. These social and emotional changes in the person with dementia will decrease caregiver burden and stress. Occupational therapists can collaborate with the caregiver to alter their approach to caregiving as the disease progresses and the persons with dementia’s abilities change. These studies by Smallfield & Heckenlaible, 2017; Kumar et al., 2014 & Yong & Price, 2014) described the beneficial effects of caregiver education about disease progression, behavior management, something about ADLs, and something about the environment (Laver, Clemson, Bennet, Lannin & Brodaty, 2014), and thereby decrease caregiver burden and improve aging in place for older adults with dementia. Occupational therapists can educate caregivers regarding activity analysis, disease progression, behavior management, and environmental influence on occupational performance (Laver, Clemson, Bennett, Lannin & Brodaty, 2014). The programs selected for this support tool provide education to caregivers on one or more of these topics. As an occupational therapist, this capstone student acknowledges the importance of these topics for caregiver education, which many are included in the support tool and many programs included are created by occupational therapists. The programs selected for this support tool provide education to caregivers on one or more of these topics. As an occupational therapist, this capstone student acknowledges the importance of these topics for caregiver education, which many are included in the support tool and many programs included are created by OT. The programs included in the support tool will
provide direct intervention for these topics, however, the intervention principles are guiding the creation of the tool and caregiver education.

Occupational therapists utilize models to guide how a therapist views a situation, a client, and uses this information to guide therapeutic interventions. The Occupational Adaptation (OA) model was developed by Schkade & Schultz (1999) and is based upon the central construct of improving adaptability rather than improving functional skills. Occupational Adaptation is a non-hierarchical, normative process that occurs most frequently during periods of change or transition (Schkade & Schultz, 1992a). This model promotes a process to form a new desired sense of self and identity during significant periods of change (Grajo & Boiselle, 2018).

Occupational adaptation or adaptive capacity is used to describe the process by which a person experiences occupational response and change due to a challenge (Schkade & Schultz, 1992b). Relative mastery is the client’s self-reflection or assessment of performance and occupational response that evaluates the effectiveness of response, effectiveness of successful achievement of a goal and personal satisfaction (Schkade & Schultz, 1992b). Function is defined as the ability to engage in occupations within a specific environment with relative mastery. Dysfunction within this model occurs when a person’s typical response is no longer sufficient for the challenge of the occupation, and thus demands a different action to achieve a successful occupational outcome (Schkade & Schultz, 1992b). The model of OA is constructed based on three primary elements which encompass the person, the occupational environment and the interaction of the two to promote occupational performance (Schkade & Schultz, 1992). The person’s sensorimotor, cognitive, and psychosocial traits influence how they interact with an occupational challenge and the environment. In this capstone, caregivers’ internal traits affect
how they perceive and adapt to the occupational performance challenge of providing care for someone with dementia.

The tool will impact both the caregiver’s traits and the occupational environment, the home. The person with dementia’s home may contain barriers that impact their participation or the caregiver’s ability to provide adequate care.

Caregivers are required to adapt their approach to caregiving as the person with dementia’s abilities decrease. Caregivers must trial new techniques and modifications to address the demands of the person with dementia’s abilities and environmental barriers. Additionally, the caregiver’s own occupational repertoire significantly changes when caring for a person with dementia.

Familial caregivers must adapt their approach and technique of caregiving to accommodate the progression of dementia and the loss of persons with dementia’s abilities and skills. In a phenomenological study by Bontje, Kinebanian, Josephsson, and Tamura (2004), researchers sought to explore the experiences of occupational adaptation in older adults with physical disabilities. Participants reported identifying solutions to constraints on their occupational functioning that required assistance from others. Additionally, creating solutions to overcome occupational constraints ranged from simple actions to multiple trials and experimentation (Bontje, Kinebanian, Josephsson, & Tamura, 2004). These solutions involved modifying the environment or their approach to occupational engagement. According to the occupational therapy practice framework, education from an occupational therapy practitioner involves the, “imparting of knowledge and information about occupation, health, well-being, and participation” (p. S30). Occupational therapists can provide education to family caregivers of people with dementia to help them adapt behaviors, habits, roles, and routines. Caregiver
education is a useful intervention for familial caregivers to adapt their approach to caregiving and achieve occupational mastery.

The caregiver education support tool will provide an opportunity for caregivers to self-reflect and analyze their caregiving strategies that may no longer be the most effective. Using occupational adaptation as the theoretical basis, the support tool will connect caregivers with evidence-based caregiver education programs that will allow caregivers to adapt and change to meet the demands of caring for a person with dementia.

Caregiver education is frequently researched, due to the high number of family caregivers. Education-based intervention frequently targets and reduces behavioral symptoms for community-dwelling older adults with dementia (DiZazzo-Miller, Samuel, Barnas & Welker, 2014). Researchers have sought to evaluate the efficacy of caregiver education, in addition to the feasibility and practicality of application to decrease negative dementia-related behaviors and improve success of aging in place. A systematic review conducted by Parker, Mills, & Abbey (2008), sought to assess the effectiveness of education interventions that support caregivers caring for people with dementia at home. Thirty-four of the forty articles included in this review were randomized control trials that evaluated the efficacy of the education intervention on depression, health, well-being, self-efficacy, and burden. Psycho-educational and multi-component education that include caregiving skills application and practice, socio-emotional, and psychological support, and support groups to help were demonstrated to improve caregiver depression, burden, and psychological anxiety and stress. Researchers concluded that multi-component interventions had significant positive impacts on self-efficacy, depression, and burden.
Based upon this systematic review, Parker, Mills, & Abbey (2008) concluded with some implications for practice for educating caregivers about dementia that included active participation in caregiver education, individualized programs addressing negative behaviors, and opportunities for caregivers to demonstrate and apply education. The caregiver education programs included in the support tool are evidence-based and utilize these techniques to improve caregiver and care receiver outcomes.

**Delivery of Caregiver Education**

Even though there are a variety of formats of education, including in-person, written form and online, caregivers report they are not receiving adequate proactive education (Mastel-Smith & Stanley-Hermanns, 2012). Caregivers most frequently receive education for a significant issue or challenge retroactively. Peterson, Hahn, Lee, Madison, & Atri (2016), conducted semi-structured interviews with 27 familial caregivers to identify triggers, barriers, and preferences for seeking education related to dementia and dementia care. Many of the caregivers that participated in the study reported a slow, insidious decline of the care receiver and did not know when to seek education until a troubling or upsetting event occurred. Participating familial caregivers reported seeking information from a physician or the internet, with poor results and unreliable information. Additionally, caregivers interviewed by Mastel-Smith & Stanley-Hermanns, (2012), reported the education they received was often too generalized and did not always address the caregiving challenges they were experiencing.

According to a large national study conducted in 2015, caregivers seek information from several sources. Twenty-two% of caregivers receive education from physician, 11% from nurses, 20% from family and friends, 11% from other health care professionals, and 53% from the internet (NAC & AARP, 2009). The National Aging Council (2018) and Peterson, Hahn,
Lee, Madison, & Atri, (2016) further explores these findings regarding who provides caregiver education, they concluded families would prefer to turn to their primary physician for education, however, this education is often insufficient due to the limited time spent with the physician (Peterson, Hahn, Lee, Madison, & Atri, 2016).

Caregiver education is most commonly offered through workshops, home visits, and the internet. Danzl et al., (2016), examined families’ experiences receiving education from health care providers to determine which method of education was most preferred. Family members reported in-person education was useful to interact with the educator and receive information specific to their person with dementia. Although in-person education was viewed favorably amongst caregivers, there were significant disadvantages to in-person education. Caregivers reported challenges with workshops because they had to find someone to care for the person with dementia while they were away (Danzl et al., 2016).

Families need prolonged and repeated education to ensure the caregiver’s feel competent in the material. Participants felt home visits were useful in this regard; however, they questioned the reliability of the home visitor. While the caregivers identified the internet as the most accessible means of education, they were unable to ask specific questions, may not have access to the internet, and they were once again unsure of the reliability of information (Mastel-Smith & Stanley-Hermanns, 2012). Written education, identified as the most useful method of education by Danzl et al, 2016), allows caregivers to re-read the information to ensure understanding. Caregivers also described in-person education as useful because it allows for interaction with the educator as well as education that is specific to their care receiver or situation. While typical written education lacks this interactive and client-specific component, the support tool developed
in this capstone will implement an interactive component through self-reflection and a Likert scale questionnaire to provide client specific education program recommendations.

**The importance of self-reflective learning.**

Caregivers can complete self-reflective activities to ensure they are receiving education specific to their needs. Dur et al., (2014) developed an occupational balance self-reflective activities measurement tool, based upon interviews with 90 people with chronic illnesses. Researchers used the experiences of the participants to guide the creation of a self-report outcome measure, which showed good construct and internal validity (Dur et al., 2014).

Carbone and Gugliucci (2015) sought to determine the most effective means for educating caregivers of older adults with delirium. Researchers reported having the participants guide the creation of the outcome measure improved the validity and usefulness to participants. Additionally, having participants self-report proved to be a valid and trustworthy means of determining change on the measurement tool.

One of the more effective interventions included a family reported assessment on care receiver behaviors, which corresponded to written material they could refer to. Although a different diagnosis, dementia and delirium share similar behavior manifestations and can burden caregivers comparably. Researchers concluded that a multi-method learning including self-reflection, psychosocial support, and multi-topic learning was the most effective caregiver education. In addition to education on multiple topics, researchers identified multi-component education comprised of both self-reflection and written material was the most effective method to deliver caregiver education (Carbone & Gugliucci, 2015).
Content of Caregiver Education

Activities of daily living.

The Occupational Therapy Practice Framework identifies caregiving as an instrumental activity of daily living. Instrumental activities of daily living support daily life occupations that, “often require more complex interactions” (p.S19). Although caregiving certainly requires complex interactions, family caregivers generally receive no formal training regarding caregiving skills when taking care of loved ones with dementia (DiZazzo-Miller, Samuel, Barnas & Welker, 2014; I think you have reported that other researchers said the same thing; include a few more here). Without adequate education, caregivers are unable to provide quality assistance, modifications, and cues necessary to assist the person with dementia in performing daily occupations (DiZazzo-Miller, Samuel, Barnas & Welker, 2014). Furthermore, Dizazzo-Miller, Samuel, Barnas, & Welker, (2014), report that caregiver education programs focused on activities of daily living of the care recipient demonstrate longer-term impacts for performance and caregiver confidence in assisting when compared to programs focused on social participation and leisure pursuits (DiZazzo-Miller, Samuel, Barnas & Welker, 2014; Letts et al., 2011).

Most studies about caregiver education focus on informal, familial caregivers to improve their ability to care for an adult with dementia. A randomized control trial by Sloane et al., (2004) evaluated the effect of person-centered showering and towel bath on aggression and agitation for older adults with dementia. Researchers found a statistically significant decrease in agitation, aggression, discomfort, and caregiver burden with the use of person-centered showering and towel bath (Sloane et al., 2004). Based upon the results of Sloane et al., (2004) and Wolf & Czekanski (2015) conducted scoping reviews of the literature to recommend best techniques for minimizing discomfort and agitation during bathing. Environmental
modifications, adaptive techniques, and person-centered bathing were indicated to decrease these behaviors, improve bathing participation, and decrease caregiver burden. The results of Sloane et al., (2004) and Wolf & Czekanski (2015) are echoed in a randomized control trial conducted by Gitlin, Winter, Dennis, Hodgson, & Hauck, (2010) who concluded that education for both familial and facility caregivers is, overall, an effective intervention to improve ADL performance and decrease caregiver burden and assistance (Sloane et al., 2004; Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010). These studies indicate that caregivers would benefit from caregiver education to address difficulty with care recipient’s activities of daily living; they also indicate that challenging behaviors are another primary reason for caregiver burden and need for institutionalization.

**Behavior management.**

In addition to addressing specific ADLs, it is beneficial to educate caregivers on techniques and methods to reduce negative behaviors. A pilot randomized control trial by Gitlin, Winter, Dennis, Hodgson, and Hauck (2010) tested the effects of a program titled *Advanced Caregiver Training on dementia-related negative behaviors for community-dwelling older adults*. Results indicated that the use of Advanced Caregiver Training improves caregiver confidence by enabling them to identify potential agitation triggers (Gitlin et al., 2010). The participants in the control group demonstrated increased caregiver distress and continuation of negative behaviors while participants in the intervention group, of training caregivers on specific activities and tasks they could engage the person with dementia in, indicated statistically significant symptom reduction and decreased caregiver burden (Gitlin et al., 2010). There are several limitations to this study, including the identification of underlying medical issues, which were treated during the intervention (Gitlin et al., 2010). However, caregivers reported anecdotal
benefits and easy application of this program (Gitlin et al., 2008). Although quality of life did not improve, the Advanced Caregiver Training program showed positive immediate and long-term benefits in symptom reduction and caregiver burden (Gitlin et al., 2010; Gitlin et al., 2008).

The findings of these two studies by Gitlin et al. are supported by another Gitlin et al study (2009) in which the researchers analyzed the use of a tailored activity program and purposeful use of leisure to reduce agitation (Gitlin et al., 2009). Researchers educated caregivers on meaningful activities to target specific behaviors. While tailored activity programs have been indicated to be successful in promoting occupational performance, Letts et al., (2011) performed a literature review to determine the current state of evidence for the efficacy of interventions designed to modify and maintain participation in ADLs, leisure, and social participation on promoting quality of life, and client and caregiver satisfaction. Researchers identified that purposeful use of leisure suggests the most consistent results of reduction of negative dementia-related behaviors, reduction of caregiver stress, and highest levels of caregiver satisfaction (Letts et al., 2011).

Although the specific characteristics of these caregiver education studies differed, there were commonalities in dosage, frequency, and length of intervention, which can be used to guide occupational therapists in clinical practice (Laver, Clemson, Bennett, Lannin & Brodaty, 2014). Overall, caregiver education interventions report long-term effects on reduction of frequency, intensity of behavior, and caregiver confidence in managing these behaviors (Gitlin et al., 2010). Improving family caregiver confidence in managing behaviors and providing adequate assistance has been shown to decrease negative behaviors (Gitlin et al., 2009). A limitation to caregiver education interventions was the feasibility of carryover and follow-through from caregivers (Gitlin et al., 2010; Gitlin et al., 2009).
Summary & Conclusion

Caregivers experience significant challenges when providing care for an older adult with dementia in the home and must be educated to decrease caregiver burden and, therefore, the likelihood of institutionalization of the care recipient. Due to the time-consuming and overwhelming responsibility of caregiving, familial caregivers can experience occupational imbalance, burden, and significant psychological and financial strain. Difficulty with activities of daily living and negative dementia-related behaviors are the most common cause of caregiver burden and institutionalization. The literature reports the use of a variety of delivery formats and several education interventions to decrease difficulties with ADLs and negative behaviors to promote successful aging in place, and decrease caregiver burden. Occupational therapists are in a strong position to use their holistic approach to treatment to address the person with dementia, their caregiver, and the caregiving environment.

The review of the current literature suggests that the use of self-reflections and written information can be effective methods of providing education to caregivers that will decrease caregiver burden and improve occupational balance, minimizing the risk of institutionalization of the care recipient. Literature suggests that self-reflection and written information are effective means of providing education and take into consideration the barriers identified by caregivers. At this time, there is no resource that connects caregivers to evidence-based education. Caregivers need individualized, proactive, and continued education to fit their needs and situations. This proposed caregiver education support tool will use self-reflections and a Likert scale to connect caregivers to evidence-based caregiver education programs that will meet their needs and identified challenges. Connecting caregivers to education programs will allow for
improved occupational balance, learning techniques for decreasing the degree of ADL assistance and negative behaviors, and promote aging in place.

The support tool will incorporate self-reflective activities and a Likert scale to connect caregivers to an evidence-based caregiver education program. Historically, caregivers receive limited education from various sources that are not individualized or evidence-based. The interactive component of the handbook will allow caregivers to self-analyze and reflect upon their own experiences, challenges, and priorities. This capstone will create a support tool that encompasses several evidence-based education programs that address multiple aspects of dementia, dementia care, and multi-component education to address caregiver burden, ADL dysfunction for the care receiver, and improve quality of life.
Chapter III: Methods

It is well documented in the literature that caregiving is a time-consuming, and often, overwhelming experience (Wagman et al., 2012). This sentiment was frequently echoed during this occupational therapist’s clinical practice. Caregivers often express that they were not receiving enough education from their physician, and they were unsure or unaware of where to seek additional education. Research conducted by Mastel-Smith & Stanley-Hermanns, (2012) confirmed the feelings of these caregivers with the conclusion that caregivers are often educated reactively to an event, rather than proactively.

Capstone Approach

These reported weaknesses in caregiver education are significant in light of conclusions by DiZazzo-Miller, Samuel, Barnas & Welker (2014), that caregiver education is the most supported intervention to impact caregiver burden, caregiver and person with dementia wellness, self-care, quality of life, and engagement for both the person with dementia and their caregiver. A caregiver education support tool was developed to facilitate caregivers’ self-reflection of their caregiver experience, identify education priorities and preferences and result in a recommendation of an evidence-based caregiver education program or programs that will best fit their needs. Use of the support tool will simplify the process for caregivers to find evidence-based and useful education programs that are applicable to their caregiving needs. This capstone student envisioned a support tool in which caregivers could be guided to reflect on their caregiver experience, education needs, preferences, and that could be used by caregivers independently.

In interviews with caregivers, conducted by Mastel-Smith & Stanley-Hermanns, (2012), caregivers reported the education they received was often too generalized and did not always
address the caregiving challenges they were experiencing. Heeding the lessons of Mastel-Smith & Stanley-Hermanns (2012), the support tool was developed by interviewing five caregivers of people with dementia to learn about their caregiver education experiences, their priorities for education topics and delivery format, and preferences for method, and location. Danzl et al., 2016, provided additional support for this tool as the use of written materials for caregiver education to allow for later review of the material was supported by his research.

During the development of this support tool October 2018 through December 2018, five caregivers participated in individual, semi-structured interviews. These caregivers were referred by the capstone student’s colleagues at Fox Rehabilitation. Caregiver participation in this interview was voluntary and took one hour per interview. These interviews guided the development of the support tool including the self-reflective activities (Appendix C-G) and the Likert Scale questionnaire (Appendix H).

Through an exploration of the literature and resources, such as the internet, books, research studies, and continuing education courses on disease progression, communication strategies, providing caregiver education, observing and reading about the caregiving experience, and interviewing experts during capstone residency it became clear that there are many caregiver education programs. However, the time and technical skills required to search and find these programs is extensive. Many older adult caregivers do not have access to the internet, and if they do, there is no central database that organizes and recommends specific education programs that meet specific needs and preferences. This is another reason, in addition to allowing for repetition, this capstone student developed a written caregiver education support tool that will guide the caregiver to a specific education program or programs that fulfill their needs, priorities, preferred method of delivery, and price point. The end product is an education support tool for
dementia caregivers that will lead to a recommendation of an evidence-based education program or programs that address a particular caregiver’s needs. Each caregiver education program included in this support tool will be evidence-based and meet the following criteria:

a. Caregivers of older adults with dementia are the program’s target audience
b. All programs will include one or more non-pharmacological intervention as the primary topic of education.
c. All programs included will have evidence to support the use of this program.
d. The evidence to support the use of this program should indicate positive results for the caregiver or care receiver.

The procedures of this capstone were as follows:

(1) Caregiver support tool development
   a. A semi-structured interview format was used to interview 5 caregivers to gain insight into the caregiver experience and education priorities. Each interview lasted about one hour.
   b. Thematic analysis was conducted to analyze the interview data.
(2) A Likert scale questionnaire was developed guided by the information from the semi-structured interviews in step 1.
(3) Five self-reflective activities were developed, based upon information from the literature reviewed regarding the most common causes of institutionalization for older adults with dementia.
(4) The caregiver education support tool was pilot tested with the 5 caregivers.
   a. The caregivers in step 1 spent 30-60 minutes completing the support tool
A Follow up interview with caregivers was conducted regarding utility of the support tool and to hear any additional feedback.

Participants

Five caregivers were recruited from this capstone student’s colleagues at Fox Rehabilitation. Colleagues at Fox Rehabilitation shared a recruitment flyer for this capstone project, and interested caregivers contacted by phone this capstone student who is employed as an occupational therapist (Appendix A). The capstone student conducted a brief phone screen to ensure the caregivers met all inclusion criteria and a phone interview was scheduled. Participants had to be a familial, unpaid primary caregiver and had to be providing care for at least one year. All participants had to be English speaking and available by phone or in person for an interview. The Institutional Review Board at Nova Southeastern University approved this project. Written informed consent was obtained from participants before interviews began (Appendix B).

The caregivers that participated in interviews had been providing care for five years-ten years. Of the five participants, three were providing care to a spouse and two were children. Each caregiver participated in a one hour interview, sharing their experience as a caregiver. This data was then thematically analyzed to inform the development of the caregiver support tool Likert scale.

Five caregivers participated in tool development interviews to gain insight into the caregiver experience. Data collected through the semi-structured interviews informed the development of the self-reflective activities and the Likert Scale questionnaire items that were included in the support tool. The five caregivers also participated in trialing the support tool after
tool development and provided additional feedback on utility and ease of use. The same five participants recruited from Fox Rehabilitation participated in each phase of this project.

**Methods and Instruments used to Learn About the Caregiving Experience and to Gather Data**

Several methods and instruments were used to guide the development, implementation, and analysis of this caregiver education support tool. A review of the literature, residency experiences, and caregiver interviews were used to develop the support tool and inform the development of the Likert scale. The Likert Scale portion of the support tool was used to gather quantitative data about caregivers’ preferences regarding education content, format, and delivery method and a post tool implementation interview was used to gather data to confirm the utility of the caregiver education support tool.

**Literature Review.**

A review of the literature was utilized to further understand the caregiving experience and the education caregivers are receiving. Both literature review and caregiver interviews were used to inform the support tool self-reflective activities, which the capstone student envisioned to be completed independently by caregivers who, in the future, access the tool.

**Residency Experiences.**

The residency experience was used to further enhance the capstone student’s knowledge of the current state of caregiver education by reading several books and participating in courses related to this topic. These activities allowed the capstone student to analyze the weaknesses of the current caregiver education methods and design a support tool that would be inexpensive, individualized, and flexible to the caregivers needs. In addition, the capstone student interviewed several experts in dementia care and caregiver education to gain insight into best practices to ensure the support tool was innovative and supported by experts in the field.
Interviews.

Five community-dwelling caregivers of older adults with dementia were interviewed to gain insight into their caregiving experiences. Interview questions were based upon Edwards (2015) research on interviewing caregivers (Appendix I). Transcripts of these interviews were reviewed using thematic analysis to identify, describe, and organize themes that emerged (Nowell, Norris, White, & Moules (2017). The capstone student read and re-read through each interview and coded all of the data. Nowell, Norris, White, & Moules (2017) suggest the best way to establish trustworthiness in thematic analysis is to use a template that requires justification of why each code should be included and clearly define how the code should be used as well as to use reflexive journaling. Once each interview was coded, the student began to group codes together to establish themes by using directed analysis. The capstone student’s faculty mentor also reviewed interview transcripts to eliminate bias and ensure accuracy. In order to ensure themes emerged accurately, Nowell, Norris, White, & Moules (2017) advise the use of directed analysis to identify themes using pre-existing theories or research to develop the initial coding scheme. Directed analysis is used to refine existing theories on a problem (Hsieh & Shannon, 2005). Once all of the data was coded and initial themes identified, the student revised and refined the themes. And finally, each theme was named and categorized appropriately to accurately represent the data.

After themes were identified, this data was used to guide the development of the self-reflection activities and the Likert scale questionnaire. The interview data was used as a reference to ensure all themes were being included within the support tool and guided how many items were included in the Likert scale questionnaire. Additionally, the themes identified in the interviews was used to support and validate the five self-reflection activities included in the
support tool, which were originally drafted from the five most common causes of institutionalization as identified by the literature.

**Combined Methods Approach**

A convergent parallel study design using qualitative and quantitative methods was utilized to make a caregiver education program recommendation to individual family caregivers of older adults with dementia and to correlate caregiver interview answers with Likert Scale questionnaire responses.

A convergence model is a mixed method design in which the researcher collects and analyzes quantitative and qualitative data on the same subject and results are converged during data interpretation (Creswell, 2011). This methodology involves concurrently conducting qualitative and quantitative research, analyzing the data independently, and interpreting the results together. A convergent parallel design was chosen for this capstone project as it uses qualitative and quantitative complimentary data to more completely understand the problem and provide a more comprehensive analysis of data (Cresswell & Clark, 2011). In this project, the data will be compared and used to corroborate the Likert scale responses of the interviewees with qualitative themes resulting from the five caregiver interviews. Comparing the qualitative interview to the Likert scale questionnaire will allow for convergence, divergence, contradictions or relationships between the two data sets (Cresswell & Clark, 2011).

**Data Collection for Future Instrument Refinement**

After completion of the caregiver education support tool and reviewing the education program recommendation based upon their questionnaire responses, the same five caregivers were interviewed by the capstone student to gain insight on the caregiver’s thoughts regarding the ease of use and practicality of the support tool to confirm the utility of this support tool.
Chapter IV: Results

Five caregivers participated in an interview to develop the support tool and inform the development of the Likert Scale. The same caregivers then completed a Likert Scale used to gather quantitative data about the caregiver’s experiences and data regarding preferences for education content, format, and delivery method. The qualitative and quantitative data is then compared to one another and to the literature. First, the qualitative data will be described followed by the quantitative data and then both data sets will be compared and followed by a discussion.

Caregiver Demographics

Five caregivers were interviewed after being referred from colleagues at Fox Rehabilitation, where this capstone student is employed. Of the five caregiver participants, all were female and all had at least a bachelor’s degree. Some caregivers were still employed, while others relied on retirement funds, pensions, and social security. Two of the caregivers were married to their care receiver, and one of them was in a relationship with the care receiver for nine years, but never married. The other two caregivers were children of their care receivers (Table 1). Each caregiver participated in an interview, completed the Likert scale questionnaire, and then participated in a follow up interview to assess the ease of use of the support tool. Of the five participants, all five completed all of the tasks required of them.
Table 1. Caregiver Demographics

<table>
<thead>
<tr>
<th></th>
<th>Age</th>
<th>Sex</th>
<th>Relationship to Caregiver</th>
<th>Income</th>
<th>Education level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver #1</td>
<td>64</td>
<td>Female</td>
<td>Spouse</td>
<td>50,000-75,000</td>
<td>Bachelor’s Degree</td>
</tr>
<tr>
<td>Caregiver #2</td>
<td>57</td>
<td>Female</td>
<td>Daughter</td>
<td>75,000-100,000</td>
<td>Master’s Degree</td>
</tr>
<tr>
<td>Caregiver #3</td>
<td>79</td>
<td>Female</td>
<td>Partner</td>
<td>35,000-50,000</td>
<td>Bachelor’s Degree</td>
</tr>
<tr>
<td>Caregiver #4</td>
<td>62</td>
<td>Female</td>
<td>Daughter</td>
<td>100,000-125,000</td>
<td>Bachelor’s Degree</td>
</tr>
<tr>
<td>Caregiver #5</td>
<td>80</td>
<td>Female</td>
<td>Spouse</td>
<td>35,000-50,000</td>
<td>Master’s Degree</td>
</tr>
</tbody>
</table>

Qualitative Data

Five caregivers participated in a semi-structured interview regarding their caregiver experience and education preferences. Qualitative themes identified included feelings of burden, feelings of loss, unmet education needs, and pendulum of emotions (Table 2). During the interviews, caregivers expressed that their caregiving experiences were comprised of much stress, worry, and burden. Despite this, four caregivers described moments of gratitude for the memories and relationships with their care receiver.

Table 2. Qualitative Themes and Examples

<table>
<thead>
<tr>
<th>Theme</th>
<th>Caregiver 1</th>
<th>Caregiver 2</th>
<th>Caregiver 3</th>
<th>Caregiver 4</th>
<th>Caregiver 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Burden</td>
<td>“It’s a [expletive] life when you’re hoping your spouse dies because he has no quality of life and he’s sucking”</td>
<td>“I was geographically closest, so all the responsibilities fell on me”</td>
<td>“I’m a very spiritual person and I think that’s one of the key things for me that allows me to graciously accept this responsibility”</td>
<td>“I am home alone with him all day doing this by myself”</td>
<td>“We couldn’t afford to have 24 hour caregivers so I had to move him in with me which has been hard”</td>
</tr>
<tr>
<td>Loss</td>
<td>“My kids have watched this man who was bigger than life just disintegrate before their eyes”</td>
<td>“No one has ever focused on her remaining abilities, just ‘what now’ when she loses more function”</td>
<td>“I become sad when I see who he was and who he is now”</td>
<td>“This was supposed to be the best years of our lives, but instead it’s been some of the worst”</td>
<td>“Sometimes I feel like I’m taking care of a stranger that just happens to look like my dad”</td>
</tr>
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<td>-------------------------------------------------</td>
<td>-------------------------------------------------</td>
<td>-------------------------------------------------</td>
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<td>-------------------------------------------------</td>
</tr>
<tr>
<td>Unmet Needs for Education</td>
<td>“I can go on the internet and read about it, but I know it’s not always true. I can spend hours sifting through information”</td>
<td>“We’ve only received reactive education after there is a problem and we’re in crisis mode”</td>
<td>“I haven’t received any education or gone to support groups- I’m just trying to figure it out”</td>
<td>“I’m looking for a support group but it’s hard to leave the house for a long time. I can’t leave him alone for very long- I worry too much about what could happen.”</td>
<td>“Not proper education, but I took some suggestions from peers who have encountered similar fates”</td>
</tr>
<tr>
<td>Pendulum of Emotions</td>
<td>“When I thought about my life did I think I’d be a caregiver at 70? No. But I love [him] and am lucky to have found him so I’m happy to help him.”</td>
<td>“He’s the love of my life we’ve been together for 50 years. And sometimes, I look at him now and he’s a stranger.”</td>
<td>“I grew angry with him, even though I know it wasn’t his fault. It requires more patience than I ever thought possible.”</td>
<td>--</td>
<td>“Stressful. Tiresome, draining, frustrating. Moments of gratitude though brief”</td>
</tr>
</tbody>
</table>
Quantitative Data

Following the interview, the same 5 caregivers completed a Likert scale questionnaire (Table 3). The Likert scale was comprised of seven questions regarding the caregiving experience and 22 questions regarding education topics and format. In order to interpret the data about burden, all questions were re-worded during analysis to assume the same positive wording. The first seven questions regarding caregiver experiences were also separately statistically analyzed for the mean for each caregiver, to quantify the degree to which their caregiving experience has been positive or negative. The mean for each Likert scale item was analyzed by descriptive statistics. The mean for each caregiver was also calculated to get an understanding of how much they agreed or disagreed with the Likert scale statements.

Table 3. Likert Scale Questionnaire Data (Items Rephrased for Positive Wording)

1=Strongly Disagree, 2= Disagree, 3= Agree, and 4= Strongly Agree

<table>
<thead>
<tr>
<th>Caregiver 1</th>
<th>1. I have previously received sufficient caregiver education</th>
<th>2. I enjoy my role as a caregiver.</th>
<th>3. I do not feel depressed and lonely.</th>
<th>4. I have other people I can turn to for help with caregiving.</th>
<th>5. My relationship with my care receiver is the same now as before becoming their caregiver.</th>
<th>6. I do not feel overwhelmed with my caregiving responsibilities</th>
<th>7. I do not need education to solve my caregiving challenges</th>
<th>Caregiver Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 strongly disagree</td>
<td>1 strongly disagree</td>
<td>1 strongly disagree</td>
<td>2 disagree</td>
<td>1 strongly disagree</td>
<td>1 strongly disagree</td>
<td>2 disagree</td>
<td>1.2</td>
<td></td>
</tr>
<tr>
<td>Caregiver 2</td>
<td>1 strongly disagree</td>
<td>2 disagree</td>
<td>2 disagree</td>
<td>2 disagree</td>
<td>1 strongly disagree</td>
<td>1 strongly disagree</td>
<td>2 disagree</td>
<td>1.5</td>
</tr>
<tr>
<td>Caregiver 3</td>
<td>2 disagree</td>
<td>4 strongly agree</td>
<td>2 disagree</td>
<td>2 disagree</td>
<td>2 disagree</td>
<td>3 agree</td>
<td>2 disagree</td>
<td>2.4</td>
</tr>
<tr>
<td>Caregiver 4</td>
<td>2 disagree</td>
<td>2 disagree</td>
<td>2 disagree</td>
<td>2 disagree</td>
<td>1 strongly disagree</td>
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The mean for each caregiver indicates how negative or positive they perceive their experience to be. The mean score for all caregivers indicate a negative caregiving experience. Caregivers 1 and 2 with a lower average, reported higher levels of burden and depression. Each The question average indicates the mean for all five caregivers and how much they agreed or disagreed with the questionnaire item. This average indicates how much all five caregivers agreed or disagreed with the questionnaire. A question average provides insight into commonalities of caregiver experiences. The responses from the Likert Scale were then compared to the qualitative interviews. In addition to exploring caregiver experiences, the second half of the Likert questionnaire addressed education delivery methods, topics, and price.

The second section of the Likert questionnaire discussed prices, delivery methods, and topics included 21 questions. There were five questions about price, seven questions about delivery methods, and nine questions about topics. Table 4 includes one or two questions from each topic included in the Likert questionnaire. The agreement ratio describes how many caregivers agree with the Likert questionnaire statements. All five caregivers prefer to receive education in their home and only one caregiver would also agree to receiving education online. None of the caregivers reported wanting to learn from experts, but all of the caregivers agreed learning from other caregivers was important.
Table 4. Likert Scale questions on Caregiver Education Preferences

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Data Interpretation

For ease of understanding, the qualitative and quantitative results were compared for each theme below. This comparison is followed by a brief discussion and implications.

Finding 1: Burden

Quantitative: Three of the five caregivers responded they strongly agree to the Likert Scale questions regarding burden (items 4 and 6), 3:5 caregivers responded in agreement to feeling frequently overwhelmed by caregiving responsibilities.

Qualitative: All five caregivers interviewed described feelings of burden due to the time-consuming nature of caring for their loved ones. Some caregivers were providing care for a spouse and felt obligated or responsible for them. Others, lived closest to their loved one and therefore, were responsible for providing care due to geography.
Comparison: Findings from both data sets indicate that all caregivers frequently feel burdened by the responsibility of providing care. However, while caregivers reported feeling overwhelmed and lonely, those caregivers that viewed their role as a caregiver positively were less likely to report high levels of burden.

Discussion: Consistent with research by Fauth, Femia, & Zarit, (2016) & Eska et al., (2013), caregivers’ perceptions of their caregiving role significantly impact the degree of their burden. When caregivers have more positive perceptions of their caregiving responsibility, they are less likely to feel overwhelmed and burdened. Only caregiver 3 indicated she was not burdened on the Likert questionnaire, but reported moments of burden during the interview. Fauth, Femia, & Zarit, (2016) & Eska et al., (2013) conclude that education and support resources can improve a caregiver’s perception of their caregiving role and decrease feelings of burden.

Implications: These findings suggest that providing education and resources to support caregivers would alter their perceptions of burden and therefore, improve wellness and quality of life for caregivers and care receivers.

Finding 2: Feelings of loss

Quantitative: Questions related to depression and loneliness resulted in 3 caregivers reporting agreement and 2 strongly agreeing. The question related to the change in the relationship between the caregiver and care receiver from before diagnosis to present had the strongest response from caregivers. Four out of five of the interviewees strongly agreed that their relationship with their care receiver has changed significantly since becoming their caregiver.

Qualitative: Caregivers reported that their relationship with their care receiver had changed dramatically with feelings of resentment and grief.
Comparison: Findings from both qualitative and quantitative data analysis indicates that caregivers experience loss of who their care receiver once was.

Discussion: Caregivers commonly experience feelings of loss related to a loss of the care receiver’s identity and roles (Edwards, 2015).

Implications: Due to the long and slow progression of dementia, these results indicate that caregivers often experience grief for a prolonged period of time and therefore, psychosocial supports and resources are imperative.

Finding 3: Unmet Needs for Education

Quantitative: Eighty percent of caregivers reported they have not received enough education to support their caregiving challenges. All the caregivers reported interest in participating in education specific to their experiences learning specific approaches to help their loved one. The Likert questions regarding the caregiver’s experience receiving education had one of the lowest means with a mean score of 1.8. All five caregivers strongly disagreed that they have received sufficient education. Caregivers indicated that learning specific techniques was important to them with 3:5 caregivers agreeing that it is important to them to learn specific approaches to assist their care receiver with activities of daily living, managing behaviors, or communication strategies. 5:5 caregivers prefer to have education in their home, and 1:5 caregivers was also open to receiving education online.

Qualitative: Caregivers reported varying experiences with the education they received previously, and stated they were forced to rely on unreliable information from friends or the internet. None of the caregivers have participated in formal caregiver education. During the interview, caregivers reported wanting to learn more about practical interventions and communication strategies.
Comparison: The quantitative data indicates caregivers are interested in receiving education specific to their caregiving needs and are open to a variety of delivery methods, and topics. However, 4:5 caregivers indicated price was an important factor in participation of a caregiver education program. The qualitative data addressed their previous experiences receiving caregiver education, which all caregivers reported to be inadequate or reactive rather than proactive. Three caregivers reported in the interview that they wanted to learn specific communication strategies, which was echoed in the Likert Scale with all five caregivers agreeing or strongly agreeing with the importance of learning specific strategies.

Discussion: These findings parallel the literature regarding when and from whom caregivers receive education (Mastel-Smith & Stanley-Hermanns, 2012). Caregivers report relying on physicians or the internet as their primary source of education, but are unsatisfied with the frequency, applicability, or delivery method of the education. A systematic review conducted by Olazaran et al., (2010) indicates that the most effective education is caregiver education with psychosocial supports for caregivers combined with practical caregiving strategies and techniques. This sentiment is reflected in the interview and Likert Scale responses of the caregivers in this capstone project who reported an interest in both receiving psychological support for themselves and learning specific caregiving strategies and communication techniques.

Implications: Evidence-based caregiver education should be more easily located and accessible for caregivers. Additionally, caregivers would benefit from physicians providing proactive education and resources to support both themselves and their care receiver through the disease progression.
Finding 4. Pendulum of Emotions

Quantitative: In some instances, there were inconsistencies in Likert scale responses regarding positive and negative aspects of caregiving. Caregiver 3 indicated she ‘strongly agreed’ with enjoying her role as a caregiver, but also agreed with often feeling depressed and lonely. Other caregivers reported not enjoying their caregiver role, but did not report feeling extremely depressed.

Qualitative: Caregivers described both feelings of anger and resentment and love and gratitude. All of the caregivers expressed positive thoughts, emotions, and memories toward the care receiver in the past and present, while also describing feelings of depression, anger, and worry.

Comparison: Caregivers have complex and ever-changing emotions due to the psychological strain caregiving can cause. Both Likert questionnaire responses and interview data reflect a complex range of emotions.

Discussion: Caregivers experience a pendulum of emotion, due to the complex nature of the caregiver-care receiver relationship. This sentiment is echoed in a study by Bjorge, Kvaal, Smastuten, & Ulstein, (2017) who evaluated the relationship quality and stress levels in caregivers, and concluded that the higher stress levels correlated to poorer relationship quality. Caregivers who experience greater more frequent negative emotions towards their care receiver are more likely to have a poorer relationship quality.

Implications: The pendulum of emotion illustrates another facet of the complicated relationship between caregiver and care receiver. Psychological supports and caregiver education programs providing psychosocial interventions are beneficial to address caregiver burden. Caregiver education programs that include caregiver psychological support can help caregivers manage extreme pendulum of emotions. Results from the interviews and literature
reviews indicate caregivers can experience negative emotions, burden, and a pendulum of emotions towards caregiving with little education, thus a caregiver education support tool was created so that future caregivers can explore their caregiving experience and identify caregiving support preferences for the ultimate purpose of leading to caregiver education recommendations.

**Caregiver Education Support Tool**

The caregiver education support tool will provide a solution to the challenges caregivers experience as illustrated through interviews, Likert Scale, and the literature. The support tool will simplify the process of finding evidence-based education and psychosocial support program or programs. All of the caregivers reported feelings of burden, loneliness, and being overwhelmed with their caregiving responsibilities. The support tool will allow for caregivers to self-reflect on their caregiving needs and challenges while simplifying the search for resources and education.

To reflect recommendations from the caregiving literature and the collected caregiver data, the caregiver education support tool as developed in three parts: Part I: The first portion of the caregiver education support tool is comprised of five self-reflection activities to enable caregivers to begin thinking objectively about their caregiving experience. According to Boud, Keogh, & Walker, (2005) self-reflective learning is a powerful tool for educating adults and understanding a person’s inner thoughts, experiences, and to generate awareness. The support tool was designed to include a number of self-reflective activities to replace the opportunity for self-reflection of the caregiving experience that was afforded by the interviews. Part II: a Likert scale questionnaire solidifies the caregiver’s priorities and preferences for an education program and leads to a recommendation for the most appropriate evidence-based caregiver education program. Part III: The last portion of the support tool provides a number of available education
programs; along with a description of each program are instructions about how to enroll or participate. The entirety of the caregiver education support tool can be found in Appendix J. The five reflection activities relate to the most common causes of institutionalization as supported by research (1) agitation and negative dementia related behaviors, (2) caregiver confidence in assisting with activities of daily living, (3) environmental safety and falls, (4) caregiver burden, and (5) caregiving occupational balance (Thoma-Lurken, Bleijlevens, Lexis, Hamers, & de Witte, 2017).

This scale measures level of agreement on statements regarding the caregiver experience, content, and preferences for education programs (Appendix H). Caregivers accessing the caregiver education support tool will rate each of the statements on a Likert questionnaire in which 1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree. The questionnaire will also serve as a quantitative measurement.

**Pilot Testing of Caregiver Education Support Tool**

After data collection and drafting of the support tool, the caregivers were once again interviewed to pilot test the caregiver education support tool and were interviewed on ease of use and any additional feedback. All five caregivers agreed that the five self-reflective activities tapped into many of their current challenges and enjoyed the interactive nature of the self-reflective activities. In regard to the five self-reflective activities, the caregivers all agreed the activities addressed many of their current challenges and enjoyed the interactive component. One caregiver recommended adding more examples to the behavior observation log (Appendix C) for clarity. Three caregivers reported that the self-reflective activities provided more clarity on their needs and challenges as caregivers. Another caregiver made recommendations on clarifying the directions to the self-reflective activity #4, Caregiver Confidence (Appendix F).
This capstone student re-worded the directions to make directions clearer. All five caregivers felt the Likert Scale was clear and concise and had no additional feedback. The caregivers reported the information and the format of each caregiver education program included in part III was easy to understand. However, three caregivers reported the review of the evidence for each caregiver education program was difficult to understand at times. To resolve this, this capstone student provided a glossary of research terms in the revised caregiver education support tool.

Overall, the caregivers reported the education support tool was clear and efficient and they were satisfied with the programs that were recommended. Five caregivers reported they thought this tool was very useful and could decrease some of the stress they experience. One caregiver reported that she is so overwhelmed that she, “couldn’t even think about searching for education programs” however, the tool made identifying caregiver education programs “simple and stress free”.

**Chapter V: Discussion**

Both the interview data and quantitative data from Likert scales completed by caregivers of individuals with dementia were consistent with the literature regarding caregiver burden and the caregiving experience. The data suggests that caregivers who are burdened are more likely to be depressed and overwhelmed with their caregiving role. Rodriguez-Perez et al., (2017), who found a caregiver’s perception of burden and their caregiving role greatly impacted their feelings of stress and depression. In this capstone project, caregivers that reported a positive outlook on their caregiving responsibilities were more likely to report less burden on the Likert questionnaire and less need for caregiver education. However, there was one caregiver that reported minimal burden during the interview, but in the Likert questionnaire reported she was burdened, overwhelmed, and required education. It is possible that the caregiver felt the need to
express a positive façade during the interview, however, was able to express her true feelings on the questionnaire. Other than this anomaly, the Likert scale responses reflected the caregiver’s thoughts and feelings expressed in the interview.

Throughout the interviews, caregivers expressed a wide range of emotions and feelings toward the care receiver and their caregiving role. Each caregiver expressed some feelings of gratitude toward their care receiver while also expressing feelings of anger, stress, worry, and resentment. A common sentiment throughout the interviews was worry and stress about the safety and wellbeing of the care receiver. Caregivers expressed feeling perpetually anxious whenever their care receiver was alone; however, some caregivers reported the inability to provide additional supervision from others was due to finances. The experiences of the two caregivers who were still working were consistent with the findings of Pitensberger (2006), who described the incredible challenge family caregivers must overcome with balancing work and caregiving responsibilities.

Another commonly expressed emotion throughout the interviews was anger and resentment towards the care receiver. Psychological strain and depression among caregivers are well documented in the literature, however, the shifting emotions between positive and negative emotions is not as readily discussed. This pendulum of emotions was apparent in all of the caregiver interviews. Despite the negative feelings expressed toward the care receiver, caregivers also conveyed appreciation for fond memories and moments shared with their loved one. Particularly the caregivers caring for a spouse, all spoke of their love and commitment to the care receiver. Several caregivers also expressed gratitude for the time spent with the “love of their life” and feel grateful that they are able to take care of them. Throughout the interview, each
caregiver, throughout the interview, vacillated between talking about feelings of anger and resentment and love and gratitude.

The most commonly identified caregiver challenge in the interview was feelings of loss and grief. All caregivers discussed the feelings that they were caring for a stranger, and that their relationship had changed drastically from disease onset to present. Both the interview and the Likert scale questions revealed this unexpected result. While the literature indicates that support groups are effective in providing caregiver’s a network for bereavement and peer support (Pfeiffer, P.N., Heisler, M., Piette, J.D., Roggers, M.A.M., & Valenstein, M., 2011). Several caregivers reported they had minimal interest in participating in these types of programs, instead expressing interest in one-on-one education online or in the home.

Based upon reports from the caregivers, price and delivery method would significantly impact a caregiver’s likelihood of participating in a program. While most caregivers reported they had not received caregiver education, those caregivers who had received caregiver education explained they only received education reactively after a crisis or troubling event. Reaffirming the findings of Peterson, Hahn, Lee, Madison, & Atri (2016), the caregivers interviewed for this project reported that they received only reactive, rather than proactive, education and made it clear that they would be interested in receiving education proactively prior to a problem arising.

The Likert questionnaire caregiver education topic preferences paralleled those mentioned in the interviews. The caregivers reported they would be interested in learning specific techniques and communication strategies in order to improve their relationship with the care receiver, in addition to receiving psychological support. These results indicate that caregivers identify both practical strategies and psychosocial supports are important to them.
Limitations

There are several limitations to this project. There was a small sample size of 5 caregivers so the results of this project must be applied to a larger population carefully. In addition, the Likert questionnaire did not include the same number questions with both positive and negative connotations to ensure accuracy of caregiver responses.

An additional limitation to this project was the lack of diversity amongst caregiver participants. All five caregivers were women, educated, and of middle or upper socioeconomic class. The results of this project could significantly differ based upon demographic factors.

Implications for the Future

This capstone project has created a comprehensive document offering caregivers many evidence-based caregiver education programs for dementia, that did not previously exist. The self-reflective activities are grounded in self-reflective learning principles and allow caregivers the opportunity to objectively learn from their own experiences. Literature indicates that caregivers of people with dementia do not often feel like a part of the health care team and feel unqualified to make health care decisions for their loved one. The caregiver education support tool gives them the autonomy to make decisions, become proactive and knowledgeable so they can be a better advocate and caregiver for their loved one.

This capstone project also illustrates that occupational therapy practitioners can use their knowledge to design resources to meet the needs of caregivers of people with dementia. In addition, it shows that caregivers are interested in receiving individualized, proactive education. Future studies should further explore the caregiving experience; the role education has on caregiver burden, and the efficacy of a caregiver education support tool. This capstone project
also has implications for occupational therapy education as it demonstrates one way occupational therapists can provide secondary intervention to a large population.

Conclusions

Often referred to as the invisible patient, caregivers can experience psychological and financial strain, depression, anxiety, and burden. The literature indicates education is one of the most effective interventions in addressing caregiver burden, isolation, and depression. Helping caregivers reduce their burden through offering a tool that leads to a recommendation of a caregiver education program or programs holds the potential to improve well-being and quality of life of both the caregiver and the care receiver. As the prevalence of dementia continues to rise, more familial caregiver will be required to provide care to their loved ones. Caregiver education is being recognized as a cost efficient and effective intervention for reducing caregiver burden and improving quality of life (Hungerford, Jones, & Cleary, 2014).

This capstone project used a mixed method approach to examine the lived experience of familial caregivers, identify challenges, and identify education preferences through the use of a support tool. This caregiver education support tool utilizes self-reflective learning techniques to allow a caregiver to self-identify their caregiving challenges and priorities. A Likert scale questionnaire further identifies education preferences and leads to a recommendation of an evidence-based caregiver education program or programs.

The results of this project also indicate that caregivers of people with dementia want proactive education that is individualized and meets their preferences for delivery method, topics, and cost. While many evidence-based caregiver education programs exist, they are often difficult to find or access. Caregivers reported receiving minimal education from health care professionals, and often have to rely on the internet, which may be inaccurate. Through data
analysis of 5 caregiver interviews and a Likert scale questionnaire, it appears that perceived level of burden significantly impacts caregivers’ feelings of burden, stress, and anxiety. Those caregivers who viewed their caregiving responsibility as a gift were much less likely to report feeling overwhelmed or burdened. Despite some caregivers not feeling burdened, all caregivers reported the desire for proactive education.

Further research would be beneficial to explore the efficacy of the caregiver education support tool, its impact on caregivers’ burden and wellness. Exploring the efficacy of a caregiver education support tool on burden, wellness, rates of institutionalization, and quality of life would contribute to the current state of knowledge in the fields of Alzheimer’s disease and caregiving and potentially provide an innovative and cost-effective solution to familial caregivers.

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occupational therapy guideline for older people with dementia and their carers.

*International Journal of Geriatric Psychiatry*, 27 742-748.


Appendix A
Participant Flyer

ARE YOU A CAREGIVER CARING FOR SOMEONE WITH DEMENTIA?

Nova Southeastern University Doctor of Occupational Therapy Research Study

“Caregiver Education Support Tool for Dementia Family Caregivers”

The purpose of this study is to create a support tool for caregivers to connect them with evidence-based education

- Seeking family caregivers to participate in a research study
- 1 hour interview regarding your caregiving experience
- In order to participate:
  - Must be English speaking
  - Must be available for an hour-long interview
  - Must be family caregiver for older adult with dementia

If interested please contact
Sarah Guariglia
Appendix B
NSU Social Behavioral Template for General Informed Consent Form
General Informed Consent Form
NSU Consent to be in a Research Study Entitled
Development of a Caregiver Education Support Tool for Family Caregivers of Older Adults with Dementia

**Who is doing this research study?**

College: Dr. Pallavi Patel College of Health Care Sciences, Department of Occupational Therapy

Principal Investigator: Sarah Guariglia, MS, BS

Faculty Advisor/Dissertation Chair: Dr. Catherine Peirce, PhD

Site Information: Interviews will be conducted in caregiver’s homes

Funding: unfunded

**What is this study about?**

This is a research study, designed to test and create new ideas that other people can use. The purpose of this research study is to: create a support tool to connect familial caregivers to an evidence-based caregiver education program that is most appropriate to their needs. At present, there is no universal resource or tool that connects caregivers to evidence-based education programs. By connecting familial caregivers of older adults with dementia to appropriate education programs, caregiver burden will be lessened, including the psychological, social, emotional, and financial impacts associated with caregiving for a loved one with dementia.

**Why are you asking me to be in this research study?**

You are being asked to be in this research study because of your invaluable experience and expertise in caregiving for your loved one. You are able to share the true lived experience of caregiving for a family member.

This study will include about 5 people.

**What will I be doing if I agree to be in this research study?**

While you are taking part in this research study, your participation will include a one hour face to face interview.

Research Study Procedures - as a participant, this is what you will be doing:
Participating in a 1 hour interview to share your caregiver experiences. This interview will provide insight into your lived experience as a caregiver and challenges or barriers you have faced. In order to participate in this study, you must be available for a one hour interview, speak English, and be a family caregiver for someone with dementia. The information you provide will be used to guide the development of the support tool, and ensure all questions and self-reflection activities are identified as applicable to their caregiving experiences.

Could I be removed from the study early by the research team?
You may be removed from the study early if you are unable to fulfill the one hour time requirement for an interview.

Are there possible risks and discomforts to me?
This research study involves minimal risk to you. To the best of this researcher’s knowledge, the things you will be doing have no more risk of harm than you would have in everyday life. There is a possibility that sharing your caregiver experiences may illicit strong, negative emotions. You may find some questions this researcher may ask you to be upsetting or stressful. If so, this researcher can refer you to someone who may be able to help you with these feelings.

What happens if I do not want to be in this research study?
You have the right to leave this research study at any time or refuse to be in it. If you decide to leave or you do not want to be in the study anymore, you will not get any penalty or lose any services you have a right to get. If you choose to stop being in the study before it is over, any information about you that was collected before the date you leave the study will be kept in the research records for 36 months from the end of the study and may be used as a part of the research. During each phase of the study, participants will verbally reaffirm their consent and desire to participate in this study. At any time, participants can revoke their consent and decline participation in the study.

What if there is new information learned during the study that may affect my decision to remain in the study?
If significant new information relating to the study becomes available, which may relate to whether you want to remain in this study, this information will be given to you by the investigator. You may be asked to sign a new Informed Consent Form, if the information is given to you after you have joined the study.

Are there any benefits for taking part in this research study?
There are no direct benefits from being in this research study. We hope the information learned from this study will improve the quality of life for caregivers by connecting them to education supported by research.

Will I be paid or be given compensation for being in the study?
You will not be given any payments or compensation for being in this research study.

Will it cost me anything?
There are no costs to you for being in this research study.
Ask the researchers if you have any questions about what it will cost you to take part in this research study (for example bills, fees, or other costs related to the research).

**How will you keep my information private?**

Information we learn about you in this research study will be handled in a confidential manner, within the limits of the law and will be limited to people who have a need to review this information. All interviews will be transcribed with no identifying information included. This data will be available to the researcher, the Institutional Review Board and other representatives of this institution, and any regulatory and granting agencies (if applicable). If we publish the results of the study in a scientific journal or book, we will not identify you. All confidential data will be kept securely. Data will be stored on a password protected computer. All data will be kept for 36 months from the end of the study and destroyed after that time by deleting all files.

**Whom can I contact if I have questions, concerns, comments, or complaints?**

If you have questions now, feel free to ask us. If you have more questions about the research, your research rights, or have a research-related injury, please contact:

Primary contact:
Sarah Guariglia, MS, OTR/L can be reached at

If primary is not available, contact:
Dr. Catherine Peirce, PhD can be reached at

**Research Participants Rights**
For questions/concerns regarding your research rights, please contact:

Institutional Review Board
Nova Southeastern University
(954) 262-5369 / Toll Free: 1-866-499-0790
IRB@nova.edu

You may also visit the NSU IRB website at [www.nova.edu/irb/information-for-research-participants](http://www.nova.edu/irb/information-for-research-participants) for further information regarding your rights as a research participant.

All space below was intentionally left blank.
Research Consent & Authorization Signature Section

Voluntary Participation - You are not required to participate in this study. In the event you do participate, you may leave this research study at any time. If you leave this research study before it is completed, there will be no penalty to you, and you will not lose any benefits to which you are entitled.

If you agree to participate in this research study, sign this section. You will be given a signed copy of this form to keep. You do not waive any of your legal rights by signing this form.

SIGN THIS FORM ONLY IF THE STATEMENTS LISTED BELOW ARE TRUE:
- You have read the above information.
- Your questions have been answered to your satisfaction about the research.

Adult Signature Section

I have voluntarily decided to take part in this research study.

Printed Name of Participant: ___________________________  Signature of Participant: ___________________________  Date: ______________________

Printed Name of Person Obtaining Consent and Authorization: ___________________________  Signature of Person Obtaining Consent & Authorization: ___________________________  Date: ______________________
Appendix C

Self-Reflective Activity #1

Behavior Observation Log

Behaviors can include agitation, aggression, resistance to care, or any action that may upset you.

<table>
<thead>
<tr>
<th>Behavior/Action that was upsetting to you</th>
<th>Date/ Time</th>
<th>What did you do?</th>
<th>What was the result?</th>
</tr>
</thead>
<tbody>
<tr>
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<td>Got upset and begged Bob to get out of bed</td>
<td>Bob stayed in bed until 1 pm and missed his doctor’s appointment</td>
</tr>
</tbody>
</table>

...
Appendix D
Self-Reflective Activity # 2
Identifying Caregiver Burden

Caregivers are often so concerned with caring for their loved one’s needs that they lose sight of their own well-being. Please answer the following questions.

During the past few weeks, I have...

Appendix E
Self- Reflective Activity # 3
Occupational Balance-Imbalance

Using this pie graph, chart the amount of time in a week you spend doing the following activities.

Caregiving  Home Maintenance  Self-Care  Leisure Pursuits  Social Participation

Employment  Other
Appendix F  
Self- Reflective Activity # 4  
Caregiver Confidence  

On a scale of 1-10, 1 being not confident at all and 10 being very confident, how confident are you that you are able to do the following activities without feeling uncomfortable or overwhelmed?

<table>
<thead>
<tr>
<th>Activity:</th>
<th>Score:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1= not confident at all</td>
</tr>
<tr>
<td></td>
<td>10= very confident</td>
</tr>
<tr>
<td>Dressing</td>
<td></td>
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<tr>
<td>Transfers to bed</td>
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<tr>
<td>Teeth/ Oral Care</td>
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<tr>
<td>Walking</td>
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<td>Eating</td>
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<td>Medication</td>
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<td>Bathing/ Showers</td>
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<td>Finances</td>
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<td>Shopping</td>
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<td>Toileting</td>
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<tr>
<td>Housework</td>
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<tr>
<td>Transfers to chair</td>
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</tr>
</tbody>
</table>
Appendix G
Self-Reflective Activity # 5
Home Safety & Fall Prevention
Appendix H  
Likert Scale Questionnaire

For each of the questions below, circle the response that best characterizes how you feel about the statement, where 1=Strongly Disagree, 2= Disagree, 3= Agree, and 4= Strongly Agree.

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I have previously received sufficient caregiver education.</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>2.</td>
<td>I enjoy my role as a caregiver.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3.</td>
<td>I often feel depressed and lonely.</td>
<td>1</td>
<td>2</td>
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<tr>
<td>4.</td>
<td>I have other people I can turn to for help with caregiving.</td>
<td>1</td>
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<td>My relationship with my care receiver is the same now as before becoming their caregiver.</td>
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<td>3</td>
</tr>
<tr>
<td>6.</td>
<td>I often feel overwhelmed with my caregiving responsibilities</td>
<td>1</td>
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<tr>
<td>7.</td>
<td>I do not need education to</td>
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<td>3</td>
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</table>
I want to learn more about how to provide care to a person with

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<td>8.</td>
<td>I am interested in learning more about how to manage dementia-related behaviors.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9.</td>
<td>Price is an important factor in participating in a caregiver education program.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10.</td>
<td>I learn best with face-to-face education.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11.</td>
<td>I am interested in participating in support groups for caregivers.</td>
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</tr>
<tr>
<td>12.</td>
<td>I would be able to attend an in-person education course weekly.</td>
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<td>3</td>
</tr>
<tr>
<td>13.</td>
<td>I would be interested in taking an online education course</td>
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<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14.</td>
<td>I want to learn more about managing challenging behaviors.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>15.</td>
<td>I want to learn more about how to provide care to a person with</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
dementia.

16. I want to learn more about how to communicate with a person with dementia.

17. I want to learn more about the disease progression.

18. I want to learn more about resources available to me.

19. I would spend between $0-50 on caregiver education.

20. I would spend between $51-100 on caregiver education.

21. I would spend over $100 on caregiver education.

22. I would prefer to receive education in my home.

23. I would prefer to receive education online.

24. I would prefer to receive written education.

25. Learning from other caregivers is important to
26. Learning from experts on dementia is important to me. | 1 | 2 | 3 | 4

27. Learning specific approaches to caring for my loved one is important to me. | 1 | 2 | 3 | 4

28. Learning more general information related to caregiving is important to me. | 1 | 2 | 3 | 4

29. I want to learn more about how to be better caregiver. | 1 | 2 | 3 | 4

30. I know where to look for resources and education. | 1 | 2 | 3 | 4
Appendix I

Caregiver Interview Questions

Questions have been adapted from Edwards (2015) research.

1. What is your caregiving story?
2. How did you come to provide care?
3. What is like to be a caregiver?
4. How are caregiving tasks divided up or negotiated among you, your siblings or other parties?
5. How close were you and your (the care receiver) before he/she was diagnosed with Alzheimer’s disease or related dementia?
6. How would you describe your relationship with before you became his/her caregiver?
7. Have you received education for how to care for your loved one? Who provided the education?
8. What do you feel are your biggest caregiving challenges?
9. What resources do you rely on for education or when you face challenges?
10. Would you be interested in receiving formal education?
11. Do you have preferences on where/and how it is delivered?
Appendix J
Caregiver Education Support Tool
The Caregiver’s Handbook for Dementia
A support tool in caring for yourself and loved ones

Sarah Guariglia OTR/L
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  New York University Caregiving Counseling & Support Intervention 21
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  Alzheimer’s Association 24
  COPE 25
  Skills 2 Care 26
  Taking Care of Myself 27
Introduction

This caregiver education support tool was created for caregivers. Throughout my career as an occupational therapist, I have been blown away by the perseverance and strength of the caregivers I have gotten the pleasure of working with. You are the unsung heroes.
Glossary of Terms

Evidence-Based
All of the programs included in the support tool are evidence-based. This means all of these programs have research to prove they are effective in providing certain outcomes.

Qualitative
A type of research that relates to gaining non-numerical data to learn more about a problem, to gain insight into others’ experiences, or to gain an in-depth understanding to an issue.

Quantitative
A type of research that results in numerical data based on objective measurements.

Mixed-Methods
A type of research that combines both qualitative and quantitative data. Combining these two methods provide a more thorough understanding of a topic.

Randomized Control Trial
A type of research design that uses one group that receives the intervention and one that is a control group.
Part 1

Self- Reflective Activities
Self-Reflective Activity # 1

Behavior Observation Log

Behaviors can include agitation, aggression, resistance to care, or any action that may upset you.

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</table>
Self-Reflective Activity #3

Identifying your Occupational Imbalance

Using this pie graph, chart the amount of time in a week you spend doing the following activities.

Caregiving    Home Maintenance    Self-Care    Leisure Pursuits    Social Participation

Employment    Other
Self- Reflective Activity # 4

Caregiver Confidence

On a scale of 1-10, 1 being not confident at all and 10 being very confident, how confident are you that you are able to assist your care receiver with the following activities without feeling uncomfortable or overwhelmed?

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<thead>
<tr>
<th>Activity:</th>
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<tbody>
<tr>
<td></td>
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<td>Transfers to chair</td>
<td></td>
</tr>
</tbody>
</table>
Part 2

Questionnaire
For each of the questions below, circle the response that best characterizes how you feel about the statement, where 1=Strongly Disagree, 2= Disagree, 3= Agree, and 4= Strongly Agree.

<table>
<thead>
<tr>
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<td></td>
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<td>---------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>7</td>
<td>I do not need education to solve my caregiving challenges.</td>
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<td>2</td>
<td>3</td>
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<tr>
<td>8</td>
<td>I am interested in learning more about how to manage dementia-related behaviors.</td>
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<td>I want to learn more about managing challenging behaviors.</td>
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<td>I want to learn more about how to provide care to a person with dementia.</td>
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<td>I want to learn more about how to communicate with a person with dementia.</td>
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<tr>
<td>17</td>
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<tr>
<td>18</td>
<td>I want to learn more about resources available to me.</td>
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<tr>
<td>19</td>
<td>I would spend between $0-50 on caregiver education.</td>
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<tr>
<td>20</td>
<td>I would spend between $51-100 on caregiver education.</td>
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</tr>
<tr>
<td>21</td>
<td>I would spend over $100 on caregiver education.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>I would prefer to receive education in my home.</td>
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</tbody>
</table>
23. I would prefer to receive education online. 1 2 3 4
24. I would prefer to receive written education. 1 2 3 4
25. Learning from other caregivers is important to me. 1 2 3 4
26. Learning from experts on dementia is important to me. 1 2 3 4
27. Learning specific approaches to caring for my loved one is important to me. 1 2 3 4
28. Learning more general information related to caregiving is important to me. 1 2 3 4
29. I want to learn more about how to be a better caregiver. 1 2 3 4
30. I know where to look for resources and education. 1 2 3 4
RESULTS

This page summarizes your questionnaire responses to recommend a caregiver education program. Add your total responses for the questions below.

**Recommendations based on Education Topics**

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<thead>
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**Key:**
- Less than 20: Alzheimer’s Association
- 20-29: COPE
- 30-40: Savvy Caregiver, Taking Care of Myself

**Recommendations based on Cost**

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**Key:**
- Less than 6: Alzheimer’s Association, REACH II, Reach OUT
- 7-9: STOMP, Savvy Caregiver
- 10-12 NYU-CI
# Recommendations based on Delivery Method

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</table>

- Less than 12: Savvy Caregiver, STOMP
- 12-19: NYU-CI, COPE
- 20-24: Skills2Care, Alzheimer’s Association, Taking Care of Myself
REACH II

**Background:** Resources for Enhancing Alzheimer’s Caregiver Health, commonly referred to as REACH was the result of two National Institute of Health clinical trials. Reach II was designed to address the needs of culturally diverse caregivers with the use of individualized interventions and strategies tailored to an individualized risk profile. Caregivers complete an assessment that identifies depression, burden, self-care, healthy behaviors, social support, and problem behaviors.

**Content:** Relaxation, Making the physical environment safer, how to best physically assist the care receiver, accessing social support, and behavior management.

**Format:** Focus on active skills training, problem solving, role playing, stress management techniques, and telephone support. REACH II is conducted face-to-face with 9 home visits, 3 phone sessions, and 5 support group sessions.

**Evidence:** After 6 months of participating in this program, caregivers reported significant decrease in negative dementia-related behaviors (36.3%), increased social support (24.1%), improved caregiver self-care (13.6%), decreased depression (39.0%), decreased caregiver burden (23.1%).

**Price:** Free

**More Information:** Contact your local Agency on Aging to find a certified interventionist in your area.

**Reference:**
REACH OUT

**Background:** Resources for Enhancing Alzheimer’s Caregiver Health: Offering Useful Treatments (REACH OUT) is based upon the program, Reach II. REACH OUT addresses psychosocial needs of caregivers in a more condensed time frame of 3 months.

**Content:** Includes all of the topics from REACH II, except the telephone sessions and support groups.

**Format:** Total of 3 months with 5 home visits.

**Evidence:** A study conducted by Czaja et al., (2018), studied the effectiveness of this program with a group of caregivers for 6 months. Caregivers participated in 6 face-to-face sessions, and 6 telephone sessions and telephone support groups. At the completion of the study, researchers analyzed perceived social support, burden, and depression, and self-efficacy. Caregivers reported significantly decreased depression, burden, and increased self-efficacy and feelings of social support. These changes were maintained for 12+ months after the study concluded.

**Price:** Free

**More Information:** Contact your local Agency on Aging to find a certified interventionist in your area.

New York University Caregiving Counseling & Support Intervention

**Background:** NYU-CI created by Dr. Mary Middleman, a professor of psychiatry at New York University. Dr. Middleman created this program based upon the stress process model, a lens to view how one processes stress and subsequent actions due to this process.

**Content:** Caregiver and family counseling sessions, individualized education, behavior management, communication strategies, ADL management, and crisis management as the disease progresses. Education regarding (1) how to best provide care for person with dementia and (2) how to take care of yourself.

**Format:** 6 individual and family counseling sessions, support groups, additional counseling by telephone (as needed). Phone and email support indefinitely and periodic follow ups. Also available exclusively online.

**Evidence:** This program has been highly researched after receiving multi-million dollar grants to implement in the New York area. Two hundred and six caregivers participated in a longitudinal randomized control study through a 20-year period. Caregivers reported a decrease in depression, decrease in negative dementia related behaviors and a 28% reduction in nursing home placements for care receivers. This program has also been researched in England and Australia with similar positive results.

**Price:** $$$

**More Information:** To participate in the program online visit [https://tdc.hcinteractive.com/content/welcome-families] to register.

STOMP

**Background:** Created by occupational therapist, Dr. Carrie Ciro, Skill-building through Task-Oriented Motor Practice (STOMP). This program is influenced by constraint induced movement therapy, a specialized approach to increase the use of a limb after stroke or brain injury. Dr. Ciro created this program after researching that caregivers who assist with daily activities report higher incidences of depression, anxiety, and burden. This program was created as an intervention to restore a person with dementia’s ability to participate in daily activities, as well as an education program for caregivers regarding how to continue this intervention at home and how to best assist with ADLs to prevent burden and depression.

**Content:** Uses a therapeutic intervention called motor practice to educate caregivers on how to assist people with dementia in ADLs. Uses errorless learning and repetition on specific tasks to improve carryover and increase participation of the person with dementia.

**Format:** In person, 3 hours a day for 5 days for a total of 2 weeks.

**Evidence:** STOMP has been guided by neurodevelopment theory and neuroplasticity principles to identify proper dosage of the intervention. This program is effective for those with dementia, lewy body dementia, or parkinsonism. In a study of 6 people with dementia and their caregivers, after completing this program, caregivers reported significant decrease in their burden, depression, and the amount of assistance the person with dementia required.

**Price:** Varies $--$

**More Information:** Contact Dr. Carrie Ciro at cciro@kumc.edu for more information on how to participate.

Savvy Caregiver

**Background:** The Savvy Caregiver is intended to train caregivers on the basics of caregiving and the progression of dementia. It trains caregivers to think objectively during stressful times to prevent a negative emotional response, which can negatively impact the person with dementia.

**Content:** An introduction to dementia, caregiver self-care, the anchors of enjoyable involvement, levels of thinking and performance, strengthening the family as a resource for caregiving, communication strategies, and skills training.

**Format:** 12-hour education program delivered in 2 hour sessions for 6 weeks. Also available on DVD or CD.

**Evidence:** In a randomized controlled trial, this program was effective in reducing caregiver burden, depression, and minimizing the caregivers’ emotional response to negative dementia related behaviors.

**Price:** $$

**More Information:** To participate, please visit https://www.hcinteractive.com/families

Alzheimer’s Association

**Background**: Founded in 1980, the Alzheimer’s Association is the largest health organization dedicated to research, education, advocacy, support, and resources to people with dementia and their families.

**Content**: The Alzheimer’s Association offers many different education programs and support groups. In their 4-part caregiver series, neurologists, physicians, elder care attorneys, and social workers provide education on how to navigate the health care system for a loved one with dementia. The association also offers programs on caregiver health, information on the disease, communication strategies, and financial and legal planning resources.

**Format**: The Alzheimer’s Association offers virtual, in person, and telephone support programs.

**Evidence**: Seven randomized control trials involving 869 caregivers analyzed the efficacy of support groups for depression, anxiety, and social isolation compared to typical treatment. A significant number of caregivers reported increased social isolation and decreased depression after participating in support groups (Pfeiffer, Heisler, Piette, Roggers, & Valenstein, 2011).

**Price**: Free

**More Information**: Please visit https://www.alz.org/help-support/community/support-groups to sign up for in person or virtual support groups.

COPE

**Background:** Care of Persons with Dementia in their Environments (COPE), is an education program designed to optimize physical health of both the person with dementia and their caregivers. This program is delivered by trained occupational therapists.

**Content:** Based upon an interview and functional assessment, the occupational therapist will create an individualized caregiver education program that addresses how to use the person with dementia’s strengths to encourage participation, general health concerns, home modifications, potential medication side effects, communication strategies, and caregiver health.

**Format:** This program begins by an occupational therapist conducting an interview to determine the person with dementia’s current roles, routines, habits, and interests. Next, the therapist conducts a cognitive and functional assessment to identify the person with dementia’s strengths and deficits. This program occurs in 10 sessions over 4 months with an occupational therapist and 1 telephone session with a nurse.

**Evidence:** Twelve caregivers that participated in this program reported increased well-being, confidence, and a reduction in caregiver identified concerns. The results lasted over 9 months for caregivers.

**Price:** Free through state programs or may be covered by insurance.

**More Information:** This program is being offered in some Medicaid Home and Community-Based Services programs. Visit https://cdpc.sydney.edu.au/research/maintaining-function/cope-program/ to find a program near you.

Skills2Care

**Background:** Skills2Care is a home-based program to support family caregivers with specific strategies and techniques. This program is based upon personal control theory which describes the use of adapting the environment and changing emotions or thoughts.

**Content:** specific techniques and strategies to decrease negative dementia related behaviors, activities of daily living, instrumental activities of daily living, communication, cueing, modifying the environment, and any specific concern the caregiver identifies.

**Format:** Five, 90-minute home visits by an occupational therapist.

**Evidence:** There is significant research to support the use of this program. In a randomized control trial, participants demonstrated increased self-efficacy, and more likely to use better problem-solving strategies at six and 12 months after the study.

**Price:** Varies.

**More Information:** Can be covered under Medicare, private pay or through aging service networks supported by the National Family Caregiver Program. Contact Laura.gitlin@jefferson.edu for a Skills2Care trained therapist near you.

Taking Care of Myself

**Background:** This program was created by Dr. Francine Ducharme, a physician in Montreal. This program is a psychoeducational group geared to identify stressors, empower caregivers to identify their strengths and their perception of stress and anxiety, and to implement coping strategies.

**Content:** This program consists of 10 90 minute sessions for groups of six to eight caregivers. Each session will address learning to advocate for yourself and loved ones to health care providers, how to avoid emotional distress, how to deal with caregiving challenges, identifying a support and resource network, and how to begin the grieving process.

**Format:** This program uses discussions, written exercises, and role playing facilitated by the group leader, a health care professional.

**Evidence:** A mixed methods design was conducted to evaluate the implementation and effects of this program for family caregivers. Eighty-one caregivers participated in this program. At the completion of this program, caregivers reported a more positive perception of their caregiving role, strengthened support network, and improved problem-solving skills. Interviews indicated that caregivers felt more empowered in their caregiving responsibilities and less stressed.

**Price:** Varies

**More Information:** For more information, visit www.chairedesjardins.umontreal.ca

The simple act of caring, is heroic.

-Edward Albert