

2021

Early Bird Caregiver Education: A program to support caregivers of individuals living with early stage dementia or memory loss or other cognitive impairments

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<https://doi.org/10.33015/dominican.edu/2021.OT.02>

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Recommended Citation

Lopez, Mia; Trees, Tyler; and Albee, Brock, "Early Bird Caregiver Education: A program to support caregivers of individuals living with early stage dementia or memory loss or other cognitive impairments" (2021). *Occupational Therapy | Graduate Capstone Projects*. 28.

DOI: <https://doi.org/10.33015/dominican.edu/2021.OT.02>

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This thesis, written under the direction of the candidate's thesis advisor and approved by the program chair, has been presented to and accepted by the Department of Occupational Therapy in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy.

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**Early-Bird Caregiver Education Program: A program to support individuals living with
early-stage dementia, memory loss, or other cognitive impairments**

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A culminating capstone project submitted to the faculty of Dominican University of California in
partial fulfillment of the requirements for the degree of Master's of Science in Occupational
Therapy

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San Rafael, CA

December 2020

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Abstract

The number of individuals living with dementia continues to rise every year, with the need for caregiver education increasing as a result. Occupational therapists (OTs) have the skills and training needed to educate caregivers on how to care for not only themselves, but their loved one as well. The Early-Bird Caregiver Education Program was created to support caregivers of individuals living with early-stage dementia, memory loss, or other cognitive impairments in providing the highest quality of care possible, while also maintaining their own well-being. The program is intended to be led by an occupational therapy practitioner and aims to provide OTs with an evidence-based, virtual training and support program. The program consists of three sessions, each of which are approximately 40 minutes long, and will be conducted in a group, telehealth setting. The three sessions will cover various topics including: the remaining abilities of individuals living with dementia, communication strategies, activity modification, occupational balance, and caregiver health management. The implementation guide, which is informed by current evidence, includes instructions on how to implement the sessions, and will be available on the DUC Healthy Aging website. Though this program was unable to be implemented in its intended format due to COVID-19, the evidence found through creating this program inspired the creation of a level II fieldwork opportunity for Dominican University of California OT graduate students, who were able to conduct virtual one-on-one sessions with caregivers of individuals living with dementia. Though the Early-Bird Caregiver Education program has yet to be implemented due to COVID-19, program developers were able to conduct a survey and collect data on the potential value of the program, with the results indicating that the material included in this program are necessary and meaningful for caregivers of IlwD.

Acknowledgements

We would like to thank the Occupational Therapy Department at Dominican University of California for affording us the opportunity to deepen, challenge, and expand our understanding of occupational therapy. We would also like to give special thanks to Dr. Gina Tucker-Roghi for her support throughout the entirety of the Capstone process. We are incredibly grateful for her guidance, optimism, and advice. Finally, we would like to acknowledge four Dominican University of California Occupational Therapy students for so willingly sharing their fieldwork experiences: Jordan Hoss, Victoria Jess, Carleigh Robinson, and Molly Vilaithong.

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of a Geriatric Academic Career Award totaling \$300,000 with zero percentage financed with non-governmental sources. The contents are those of the authors and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS or the U.S. Government

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Introduction

Each year, more than 16 million Americans dedicate 17 billion hours of unpaid care for family and friends with Alzheimer's disease and related dementias (Centers for Disease Control and Prevention, 2019). Due to a lack of support and education concerning early-stage dementia, there are many caregivers in today's society who are experiencing physical, emotional, and social health challenges (Tatangelo, McCabe, Macleod, & You, 2018). The demands of caregiving have been found to leave caregivers with a decreased quality of life (QOL), directly impacting their ability to offer quality care (Tatangelo et al., 2018; Ducharme, Levesque, Lachance, Ducharme et al., 2011). Research shows that 75% of Alzheimer's and dementia caregivers are concerned with maintaining their own health, and sixty percent of Alzheimer's and dementia caregivers are experiencing high or very high levels of stress (Alzheimer's Association, 2020). While programs that focus on the health of caregivers for individuals living with early-stage dementia (ILwD) are needed, there are currently very few in existence (Heid et al., 2019). As a result, the needs of caregivers remain a top concern and priority. Educating caregivers on the symptoms of early-stage dementia, as well as how to modify their physical and social environment in order to support their loved one, while maintaining their own mental health, will benefit both ILwD and their caregivers.

The Early-Bird Caregiver Education program offers a three session early-education program for caregivers of ILwD. The first session focuses on education concerning the signs, symptoms, and remaining abilities associated with early-stage dementia. During the second session, caregivers are educated on activity modification. Participants explore the significance of meaningful occupations, learn how to modify a pre-selected activity to match the cognitive abilities of individuals in early-stage dementia, and practice adapting an activity of their

choosing. The final session focuses on caregiver burnout and techniques to maintain one's mental and physical health, as well as occupational balance. While it is not possible to stop the progression of dementia, occupational therapists can educate caregivers on strategies aimed at decreasing caregiver burden -- allowing caregivers more time to engage in occupations they find meaningful while providing high quality care for their loved one.

Background and Review of the Literature

Dementia

There is a difference between changes in cognition due to aging and changes due to a medical condition -- such as dementia. Dementia is not a disease but rather a group of symptoms (Mayo Clinic, 2019). These symptoms can present in numerous ways. Individuals with dementia can experience a range of minor to major changes in their cognitive and psychological well-being. In the later stages of dementia, memory, thinking, and social abilities are gravely impacted, leading to severe occupational and daily life changes (Ismail et al., 2016; Auning et al., 2011; Alzheimer's Association, 2019; Duong, Patel & Chang, 2017).

Dementia progresses through three main stages: early-stage, middle-stage, and end-stage. Each of these stages are unique in that they are composed of different symptoms, functional limitations, and levels of caregiver burden (Mayo Clinic, 2019; Bradford, Kunick, Schulz, Williams, & Hardeep, 2009). Early identification of dementia is critical due to the severity of the symptoms increasing as dementia progresses into the end-stage. However, despite there being a need for early identification, it rarely happens (Bradford et al., 2009).

Though dementia is becoming increasingly prevalent in the senior population, it is sometimes challenging for physicians to distinguish the difference between dementia and normal aging. The total number of individuals living with dementia continues to rise each year, with an estimated 5.8 million Americans currently living with dementia (Alzheimer's Association, 2019b). The financial value of the 18.5 billion hours of care provided by unpaid caregivers equals approximately \$235 billion (Alzheimer's Association, 2019b). Though the current number of people being affected by dementia is large, the statistics cited do not capture the entirety of this population; there are still a number of people who meet the diagnostic criteria

for dementia who have not been diagnosed by a physician (Alzheimer's Association, 2018). On the other hand, there are countless people who have been diagnosed by a physician as having dementia without ever being formally told their diagnosis. Based on a report from the Centers of Medicare and Medicaid Services (CMS), it was found that half of ILwD were not informed that they had been given a diagnosis of Alzheimer's or other related dementias -- despite the diagnosis being present in their medical record (Alzheimer's Association, 2018). As the various forms of dementia continue to be underdiagnosed and underreported, a significant number of Americans will continue to live with dementia and not even know it. Furthermore, as this number continues to rise, more people will continue to experience occupational deprivation, and more caregivers will continue to provide care to their loved ones without the proper education on how to do so. This overall lack of education has the potential to cause decreased QOL for not only ILwD, but for their caregivers as well.

Though previously referred to as "dementia," the term has been replaced as "major and minor neurocognitive disorder" within the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). The criteria for a major and minor neurocognitive disorder includes a significant impairment in one or more of the following categories: memory, language, execution of purposeful movement, recognition/familiarity, visuospatial function, and self-control/management (Keefover, 2013). The identification of these impairments has proven to be difficult due to these symptoms mirroring those that are believed to be characteristic of the typical aging process. Dementia normally presents with changes in the following five domains: cognitive changes, psychiatric changes, personality changes, behavioral response changes, and changes in daily occupational functioning (Ismail et al., 2016; Auning et al., 2011). These

changes often result in the identification of early-stage dementia and gradually become more pronounced as dementia progresses

Stages of Dementia

Dementia progresses through three predictable stages. Though ILwD are experiencing cognitive changes, in the early stage, they still have the ability to learn to cope with their diagnosis (Bunn et al., 2012). During the early-stage, ILwD are still capable of making decisions for themselves and their families regarding the implications of the disease, and therefore, should be included in the decision-making process (Bunn et al., 2012). The symptoms within early-stage dementia can vary in severity from person to person. For some, it may not be as pronounced, and individuals may still be able to function when performing some daily activities (Alzheimer's Association, 2019). Though many people mistake the signs of early-stage dementia for older age, it is important to note that the changes associated with dementia are far more severe than those seen in the typical aging process (Alzheimer's Association, 2019). While some individuals living with early-stage dementia may still be able to drive, work, and engage in other daily occupations, they are often experiencing challenges with their planning and organizing abilities at the same time (Alzheimer's Association, 2019). As dementia progresses to the middle and end stages, the extent of the brain damage makes it difficult to engage in daily activities and additional assistance is needed. In middle-stage dementia, the symptoms start to become more noticeable (Alzheimer's Association, 2019). Individuals in this stage may experience forgetfulness of events and decreased problem solving in daily activities (Alzheimer's Association, 2019). As individuals progress to end-stage dementia, ILwD become more reliant on their caregivers, and typically require round-the-clock assistance when engaging in daily activities (Alzheimer's Association, 2019).

Table 1 Signs Indicating Early-Mid Stage Dementia

Domain	Signs Indicating Early-Mid Stage Dementia
Cognitive	Forgetfulness, difficulty understanding communication, difficulty thinking of words
Psychiatric	Depression, anxiety, paranoia, hallucinations
Personality	Social withdrawal, frustration, disinterest, inappropriate friendliness
Behavioral Responses	Agitation, restlessness, leaving the bed at night, wandering
Daily Occupational Functioning	Difficulty driving, forgetting recipes when cooking, difficulty with financial management, difficulty shopping, getting lost, forgetting to engage in self-care

Note: (Ismail et al., 2016; Auning et al., 2011; Alzheimer's Association, 2019; Duong, Patel, Chang, 2017)

As dementia progresses, the remaining abilities of ILwD begins to decrease, and the level of expected caregiver burden begins to rise. The caregiving challenges associated with each stage vary and are highly dependent on the remaining abilities of that specific individual.

Table 2 Dementia Stages

Table 2	Early Stage Dementia	Middle Stage Dementia	Late/End-Stage Dementia
Remaining Abilities	Independent in daily care, but may have poor quality or safety New learning is possible with some repetition	Repetitive motor actions/manual actions (movements of the muscles in the body) such. Examples include repeating a word, question, or activity over and over again. The individual may undo the	Communicates with simple verbalizations and universal gestures Responds to proprioceptive cues and maintains upright posture

Table 2	Early Stage Dementia	Middle Stage Dementia	Late/End-Stage Dementia
	<p>Simple problem-solving abilities</p> <p>Benefits from routines and familiar environments</p>	<p>work they have already done in order to do the activity again</p> <p>Correct use of objects</p> <p>Aware of locations and supported by having daily routines</p> <p>Follows one step directions as part of a simple and familiar task</p> <p>Completes simple/familiar tasks and self-care routines with cues to sequence</p> <p>Writes his/her name</p> <p>Can use the toilet, but may require reminders</p> <p>Communicates about actions and objects</p>	<p>Gross motor movements including standing and walking</p> <p>May participate in self-care by eating finger foods, moving limbs and trunk to assist with dressing and bathing, and leaning forward to swish or spit in sink during oral care</p> <p>Continence with a toileting schedule and assistance</p> <p>Visual attention to the area directly in front of the person</p>
Common Caregiver Challenges	<p>Inability to respond to ILwD's impulsive and inflexible thinking</p> <p>ILwD may demand immediate attention due to poor understanding of time</p> <p>Caring for ILwD due to recurrent hospitalization and</p>	<p>Inability to respond to ILwD's anxiety, agitation and aggression in response to stressors and environmental stimuli</p> <p>Supporting ILwD despite his/ her resistance to care and passive participation in activities</p> <p>Remembering to accommodate ILwD's decreased field of vision</p>	<p>Inability to respond to ILwD's agitation and resistance to care (especially related to mobility)</p> <p>Lack of education on how to speak to ILwD, while accommodating his/ her decreased processing time and poor ability to follow directions</p>

Table 2	Early Stage Dementia	Middle Stage Dementia	Late/End-Stage Dementia
	failed discharges Supporting ILwD in using assistive devices Self-neglect, not taking medication, and poor management of time and routine	Preventing the ILwD from falling	

Note: (Allen, Blue, Earbart, 1998; Alzheimer's Association, 2019)

Issues Related to Lack of Diagnosis

Research has shown that many primary care physicians do not feel comfortable labeling symptoms as dementia, resulting in limited opportunities for early intervention. This is mainly due to primary care physicians and caregivers feeling uneducated about the differences between the typical and atypical parts of aging (Bradford et al., 2009; Romano, Carter, Anderson, & Monroe, 2020). Furthermore, physicians have expressed an unwillingness to follow up on a referral from another healthcare provider for ILwD because they fear misdiagnosing the patient, are unsure of the usefulness of an early diagnosis, and lack assessment tools and protocols for identifying dementia (Bradford et al., 2009; Romano et al., 2020). Similarly, patient and caregiver attitudes have been found to limit the number of encounters that ILwD have with a physician, therefore limiting the opportunities for symptom recognition. These attitudes stem from the negative perceptions surrounding dementia, with patients and caregivers not wanting a diagnosis of dementia to be made. Missed or delayed diagnosis limits the opportunity for early intervention, therefore increasing caregiver burden.

A preventative and proactive approach for diagnosis and intervention serves not only ILwD but their caregivers as well. Early intervention gives caregivers time to prepare for their loved one's future care needs and provides ILwD a chance to contribute to their own care plan. Therefore, this approach has the potential to improve the QOL of both ILwD, as well as their caregivers (Bradford et al., 2009). Occupational therapists have the expertise needed to identify the remaining abilities of ILwD in all stages. Through OT screening tools and a strength-based model of care, OTs can work with caregivers and those in the early stages of dementia in order to identify strengths, impairments, and functional implications (Schaber & Lieberman, 2010; American Occupational Therapy Associations, 2019). OTs can educate caregivers on proper adaptation and compensation, such as appropriate cueing, social supports, and coping strategies, in order to increase the QOL of ILwD and their caregivers (American Occupational Therapy Association, 2019).

Screening for Stage of Dementia and Remaining Abilities

In order to provide early education concerning dementia, it is vital that early assessments and screening interventions take place. Typically, individuals are first referred to a physician because of their score on a cognitive screening test, such as the Mini-Mental State Examination (Arevalo-Rodriguez et al., 2015). If a screening score indicates that an individual has a cognitive impairment, it is important that further testing takes place. Dementia screening is often completed by physicians and may include staging using either the Functional Assessment Staging Test (FAST) or the Global Deterioration Scale (GDS) (Mougias et al., 2018; Reisberg, Ferris, de Leon, & Cook, 1988; Reisberg, 1982).

The FAST-screening method indicates what level of daily functioning an individual has lost. Information is gathered through either talking to the ILwD's caregiver or to someone who is

close to the client. The FAST consists of eleven subcategories and seven stages, with a higher stage correlating to more severe symptoms (Reisberg et al., 1988). When an individual's score falls within the fourth stage, they are considered to be experiencing symptoms of mild dementia (Reisberg et al., 1988).

On the other hand, the GDS screening method provides physicians and caregivers with a general description of what to expect cognitively, physically, and behaviorally of an ILwD. The GDS separates the expected cognitive functioning of an ILwD into seven stages (Mougias et al., 2018; Reisberg, 1982). Under the GDS, stages one through three are considered pre-dementia stages, and stages four to seven are considered the dementia stages. Stages five to seven mean that the individual can no longer live without assistance (Reisberg, 1982). The GDS can be used as a reference when observing an ILwD's behavioral characteristics to get a general idea of what to expect of that individual (Mougias et al., 2018; Reisberg, 1982).

While the FAST and GDS screening methods are useful tools to identify the stage of dementia, OT assessments, such as the Allen Cognitive Level Screen – version 5 (ACLS-5), focus more on identifying functional cognition. Rather than simply identifying that there is a cognitive deficit, the ACLS-5 identifies overall levels of awareness, gross motor movements, manual actions, engagement in familiar activities, and one's ability to learn and plan new activities (Allen, 1991). OTs help to identify key remaining abilities and strengths for individuals in early-stage dementia. Through collaboration with a physician, OTs can share their assessment findings in order to further support the diagnosis process. Using a comprehensive battery of assessments, OTs are able to gather specific information on the ILwD's remaining cognitive abilities and develop an intervention plan that integrates health promotion, remediation, maintenance, and modification techniques (The American Occupational Therapy Association,

2017; Pimouguet et al., 2019). With early assessment and intervention comes an opportunity for early education and caregiver support. When caregivers and ILwD are informed of the expected symptoms and best care practices, ILwD have a better chance of maintaining their highest level of functioning -- whether it be at home or out in the community

Occupational Changes among Individuals Living with Dementia

The symptoms associated with early-stage dementia can cause significant occupational changes in ILwD. These changes are exacerbated when a cognitive impairment is paired with neuropsychiatric behaviors, with the resulting symptoms having major functional implications (Thompson, 2008; Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012; American Occupational Therapy Association, 2017). Some of the main psychological and behavioral symptoms that ILwD may present with include agitation, aberrant motor behavior, anxiety, elation, irritability, depression, apathy, disinhibition, delusions, hallucinations, and sleep or appetite changes (Cerejeira et al., 2012). These symptoms make performing basic activities of daily living (BADLs) and instrumental activities of daily living (IADLs) challenging for ILwD as the symptoms progress over time (Borsje et al., 2015; Thompson, 2008). With frequent mood and personality changes, ILwD may become confused and anxious when trying to participate in daily activities. When these emotions are paired with a fading memory, it can escalate to anger -- especially when ILwD attempt to participate in novel tasks or activities. Additionally, symptoms such as social withdrawal, loss of appetite, decreased sleep, fatigue, and suicidal thoughts can also impact occupational functioning (Thompson, 2008). Ultimately, all of these symptoms have the potential to lower the QOL and occupational performance of ILwD. The majority of individuals with dementia will eventually need assistance with some- if not all- of their daily activities (Alzheimer's Association, 2019a). However, this does not mean that ILwD need to

give up the occupations that they love, as many activities can be modified to fit the individual's level of cognitive ability.

Interventions to Address ILwD

Though there is not a cure for dementia, early intervention is crucial when working to maintain not only the QOL of ILwD, but the QOL of their caregivers as well. Shortening the period of time between when symptoms first arise and when a diagnosis is made is critical in the treatment of dementia; the earlier the intervention is implemented, the better the outcomes will be (Prince, Bryce, & Ferri, 2011). These outcomes include delayed admittance of ILwD to an institution, as well as decreased caregiver strain (Prince et al., 2011; Pertl, Sooknarine-Rajpatty, Brennan, Robertson, & Lawlor, 2019). Currently, there are pharmacological interventions being utilized to treat dementia-related symptoms; these drug therapies are typically used during the treatment of middle and end-stage dementia. However, these forms of therapy are more likely to be impactful when implemented before extensive or permanent brain damage has begun. It is predicted that these treatments would be more impactful when used during the earliest stage of dementia -- or even before the symptoms of dementia present (Prince et al., 2011; Austrom, Boustani, & LaMantia, 2018; Arvanitakis, Shah, & Bennett, 2019; Bessey & Walaszek, 2019).

Though pharmacological interventions have been found to provide mild relief from the symptoms associated with dementia, research shows that non-pharmacological interventions, such as psychosocial and psychological interventions, should be attempted prior to the prescription of solely medication (Austrom et al., 2018). One effective form of non-pharmacological intervention for individuals living with a mild cognitive impairment or early-stage dementia is cognitive rehabilitation (CR) (Wilson, 2002). In a randomized controlled study conducted in 2019, four-hundred and seventy-five individuals living with early-stage dementia

underwent a ten-week trial utilizing CR intervention (Clare et al., 2019). Following the completion of the trial, researchers concluded the intervention with the use of a goal oriented CR intervention, which was administered by licensed therapists. Through engaging in cognitive rehabilitation, individuals living with early-stage dementia were able to increase their occupational performance and achieve their personal goals that they set in therapy (Clare et al. 2019). Through incorporating CR and other psychosocial interventions into the treatment of ILwD, occupational therapists can improve the daily lives of ILwD, which in turn increases the QOL of their caregivers as well.

Non-pharmacological interventions can include the use of everyday occupations, such as reading, physical exercise, and social gatherings as a form of treatment (Arvanitakis et al., 2019). Within non-pharmacological interventions, research has shown one form of intervention to be significantly more effective than any other form of intervention: caregiver education (Bessey & Walaszek, 2019). Though both non-pharmacological and pharmacological interventions have the potential to be successful, formal caregiver training has been found to produce the best management of dementia related behavior and psychological symptoms (Bessey & Walaszek, 2019).

It is crucial that caregivers are offered support as soon as possible when caring for ILwD. When caregivers are supported early on in the progression of dementia, they are able to gradually become accustomed to the demands associated with the role (Prince et al., 2011; Ducharme et al., 2011). This allows caregivers the chance to create and utilize plans and daily routines that will support their loved one as the symptoms progress. In order for early intervention to take place, there first needs to be an early diagnosis. In order to achieve this, there

needs to be accessible diagnostic and early-stage dementia care services, as well as caregiver education programs (Prince et al., 2011).

The Effect of Dementia on Caregivers

Dementia impacts both ILwD and their caregivers. Caring for someone with dementia can greatly impact one's daily life, with changes in one's mental and physical well-being, as well as level of occupational engagement, occurring as a result (McHugh, Wherton, Prendergast & Lawlor, 2012; Tatangelo et al., 2018). Due to these changes, caregivers and their family members can experience a decrease in their QOL, as well as a decrease in their physical and mental health (McHugh et al., 2012). Caregivers can also experience feelings of self-sacrifice and grief in relation to the changes that they are making in their own lives in order to accommodate their caregiving role (Tatangelo et al., 2018).

In a study conducted by Tatangelo, McCabe, Macleod, & You, researchers analyzed the experiences of offspring caregivers (2018). Within this study, it was found that the caregivers were susceptible to feelings of depression, hopelessness, anxiety, isolation, loneliness, and low self-worth (Tatangelo et al., 2018). In order to collect data, semi-structured interviews were conducted by researchers, with the target population consisting of twenty-four familial caregivers of community-dwelling individuals living with dementia (Tatangelo et al., 2018). Of these participants, 12 were partner caregivers and 12 were offspring caregivers. All of the conducted interviews were transcribed and analyzed and after a careful analysis of the data, five key themes emerged.

The first theme that emerged from the data discussed caregivers' overall assessment and perception of their own health (Tatangelo et al., 2018). The remaining themes included: caregivers' health needs, mental health, emotional support and social relationships, healthy diet

and exercise, and personal time (Tatangelo et al., 2018). A significant barrier for partner caregivers was that they experienced difficulty identifying their own needs (Tatangelo et al., 2018). Additionally, partner caregivers demonstrated unmet emotional support needs, as they no longer had emotional support from their partner living with dementia (Tatangelo et al., 2018). There was also an unmet need concerning time away from their caregiving role, yet the caregivers did not express an interest in leaving their loved one (Tatangelo et al., 2018). In regard to offspring caregivers' unmet health needs, it was found that their health issues were due to lack of engagement in other areas such as exercise, diet, and having time to themselves (Tatangelo et al., 2018).

Countless health issues can arise from being a caregiver for someone living with dementia. Some challenges that may arise include an inability to maintain one's physical health, psychological health, and previous lifestyle (Tatangelo et al., 2018). Family caregivers often experience high rates of depression, stress, and physical illness when caring for ILwD (Tatangelo et al., 2018). These health problems are often exacerbated by caregivers' health needs not being met, which then leads to burnout (Tatangelo et al., 2018). If caregivers are unable to take care of their own physical and psychosocial health, they cannot provide the quality of care that is needed by their loved one living with dementia. When caregivers ignore their own needs, not only does their own health decrease but so does their capacity to provide high-level care (Ducharme et al., 2011).

Another factor that contributes to caregivers' health problems is the high levels of stress that they endure. Levels of stress and uncertainty often arise following a period of transition, such as someone taking on the role and responsibilities that come with being a caregiver (Ducharme et al., 2011). In an experimental study conducted by Ducharme, Lévesque, Lachance,

Kergoat, Legault, Beaudet, and Zarit (2011), caregivers of ILwD were recruited from various memory clinics and separated into two groups: experimental and control. The caregivers who were a part of the experimental group were given a personalized intervention toolkit to follow, as well as training sessions and a scenario training program to attend, and the control group was given solely physical resources, such as pamphlets. Upon the program's completion, it was found that the caregivers who were a part of the experimental group experienced an easier role transition in comparison to those who were simply given physical resources (Ducharme et al., 2011). These individuals were found to be more confident in dealing with caregiving situations and perceived themselves as being more prepared for the caregiving role (Ducharme et al., 2011). Additionally, the participants in the experimental group were better able to plan for their loved one's future care needs, were more knowledgeable of available community services, and more frequently used coping strategies -- including problem solving and reframing techniques (Ducharme et al., 2011). While this study found that the training program increased the QOL of the ILwD, it did not reduce the stress levels of the caregivers within the experimental group (Ducharme et al., 2011). By not providing the caregivers with information on what dementia is and how it will progress, the caregivers were left feeling uninformed and unprepared as to how they should balance the responsibilities that come with being a caregiver (Ducharme et al., 2011). This specific study emphasized the importance of providing caregivers with information and resources regarding the progression of dementia in order to prevent occupational deprivation and stress related to the caregiving role.

Caregivers' stress can be further exacerbated by feelings of loneliness and depression, as well as exposure to behaviors not typically expected by their loved one (Lin, Shih, & Ku, 2019). While caregivers may not experience the symptoms listed above until the ILwD progresses to a

later stage, it is vital that these difficulties be addressed early on in order to ease the role transition.

Occupational Changes Among Caregivers of Individuals with Dementia

Just as there are occupational changes for ILwD, there are also occupational changes that take place among caregivers. Major areas of occupational change regarding caregivers include work, social interaction, and leisure (Tatangelo et al., 2018). Though it is not always intentional, caregiving can be a full-time role -- particularly when the caregiver resides with the care recipient (Tatangelo et al., 2018). While many caregivers do not view helping their loved one with ADLs or IADLs as a burden, doing so inadvertently increases the number of hours spent in the caregiving role (Lin et al., 2019). In many cases, the role of being a caregiver becomes a new form of work, with the negative behavior patterns associated with dementia only increasing the reported level of caregiver burden (Tatangelo et al., 2018). It is vital that caregivers be given outside support to ease into their role transition. Even though there is not a way to stop the progression of dementia, occupational therapists can educate caregivers on strategies aimed at decreasing caregiver burden -- allowing caregivers more time to engage in occupations that they find meaningful.

Occupational deprivation often results from the high demands of being a caregiver and an overall lack of social interaction. Occupational deprivation as described by Stadnyk, Townsend, & Wilcock (2010) is the “state of preclusion from engagement in occupations of necessity and/or meaning due to factors that stand outside the immediate control of the individual.” Many caregivers experience isolation due to feeling emotionally unsupported by their family members and friends while caring for an ILwD (Tatangelo et al., 2018). One study evaluating the needs of caregivers found that half of caregivers are living with unmet needs when it comes to spending

time away from their caregiving role (Tatangelo et al., 2018). Furthermore, research shows that caregivers can also experience social isolation if they are reluctant to hire an outside source to care for their loved one (Tatangelo et al., 2018). This hesitation was cited as a result of a perceived lack of quality, flexibility, and convenience of service (Tatangelo et al., 2018). Another reason for this hesitation was the ILwD not wanting to attend respite care services (Tatangelo et al., 2018).

Caregivers' reluctance to use outside services is further compounded by their feelings of loyalty and obligation to care for their loved one (Tatangelo et al., 2018). While caregiving can be rewarding, it is often time-consuming. When a caregiver neglects their own needs for leisure and social interaction, occupational imbalance may occur. Occupational imbalance is defined as "a lack of balance or disproportion of occupations" (Wilcock, 1998). A study conducted by McHugh, Wherton, Prendergast & Lawlor (2012) completed multiple home visit interviews with caregivers of ILwD in order to address the concerns and needs of the caregivers. The researchers found that the promotion of the caregivers' physical and mental health allowed them the capacity to continue delivering quality care (McHugh et al., 2012). This supports the notion that providing early education on physical and mental health in a natural setting can lead to a better QOL for ILwD and their caregivers.

Caregivers of ILwD need to receive proper training and education before the symptoms of dementia progress. As the symptoms worsen, caregivers begin to provide a higher-level of care- one which is typically provided by licensed healthcare providers (Weiss et al., 2017). While there are several programs that aim to educate caregivers on self-care and stress management strategies, there are few that focus on specifically educating caregivers of

individuals living with early-stage dementia on what to expect as the symptoms progress (Heid et al., 2019).

Furthermore, while existing programs do address topics such as stress management, there are little to none that educate caregivers from an occupational perspective. Occupational therapy practitioners take a holistic view during caregiver education, in that they educate caregivers on all aspects of their being. OTs look at not only health management, occupational balance, and activity modification, but also how to care for others. Through an occupational perspective, caregivers can be educated on how to adapt occupations to fit their loved one's needs, balance their own occupational engagement in order to promote occupational performance, develop, manage, and maintain routines that promote health and wellness, and engage in community social interaction in order to gain support from individuals in similar role transitions. By providing caregivers with education on all of the topics listed above, they will be better able to support their loved one in maintaining their highest level of independence for as long as possible.

Needs and Experiences of Caregivers

There has been extensive research conducted on how caregivers' working life, psychological health, and mental health can be improved (Karlavish et al., 2003; Lee, Ryoo, Crowder, Byon, & Williams, 2020). Though there is a current lack of research concerning how caregivers cope with their stress, research has shown that caregivers often experience psychological issues due to a lack of treatment options for ILwD (Jeong et al., 2018). One study titled "Who is Caring for the Caregiver? The Role of Cybercoping for Dementia Caregivers" researched how the caregivers' communication strategies impacted their ability to provide quality care. This study analyzed the communication behaviors of one hundred and four caregivers. Researchers analyzed the information seeking and information forwarding behaviors

of the caregivers, with information seeking being defined as an individual gathering information from cyberspace on dementia, and information forwarding behaviors being defined as one actively sharing their experience of being a caregiver with other individuals. The results showed that caregivers who are forty-five years or younger are more likely to be information seeking, and caregivers who have been in the role for less than 18 months are more likely to be information forwarding than caregivers who have been in their role for a longer period of time (Jeong, Kim, & Chon, 2018).

This study found that caregivers typically use information seeking and information forwarding behaviors when gathering information (Jeong et al., 2018). These activities provide caregivers with social support, the subjective perception of other caregivers, and online psychological resources (Norbeck, Lindsey, & Carrieri, 1981; Jeong et al., 2018). The internet can play an important role in relieving caregivers' negative emotions and physical symptoms (Jeong et al., 2018). However, this study revealed that caregivers tend to cope with issues related to the ILwD, rather than the issues related to their own health or occupational balance (Jeong et al., 2018).

Communication behaviors can help caregivers be more prepared when assisting ILwD. This study emphasized the positive effects of communication behaviors on outcomes through the coping process when assisting ILwD (Jeong et al., 2018). Communication behaviors have a significant impact in cyberspace and can help caregivers learn to cope with dementia both cognitively and physically (Jeong et al., 2018). Therefore, it is important for caregivers to communicate their needs in order to promote a better QOL and experience for themselves, as well as ILwD

OT Interventions to Address Caregivers

It can be challenging for families and physicians to recognize the early signs and symptoms of dementia. This is particularly true due to the course of dementia varying for every individual (Cotter, Spriggs, & Razzak. 2017). The loss of cognition and function can occur rapidly over the course of many years. One article titled, “Advance Care Planning in Early Stage Dementia,” discussed why it is essential to provide training and early education to caregivers in the early stages of dementia (Cotter et al., 2017). This article explained that training has the potential to increase the level of trust between caregivers and ILwD as they work together to create advanced care plans. Advance care planning is focused on conversations that discuss specific health conditions, future care options, and personal wishes towards the end of the ILwD’s life (Cotter et al., 2017). In addition to physician-led discussions around resuscitation, artificial nutrition, hydration, and advanced level care, occupational therapists can support caregivers and ILwD in maintaining person-centered care by leading important conversations concerning the ILwD’s future preferences concerning habits and routines (Cotter et al., 2017). In order for caregivers to improve the QOL of ILwD, they need to know what their loved one desires. Due to dementia being progressive and causing a loss of decision-making and communication abilities, it is essential that these conversations take place during the early stages of dementia.

Early diagnosis of dementia allows for the implementation of early intervention, which has been shown to positively affect one’s ability to provide high quality care (Bradford et al., 2009). Currently, there are minimal guidelines for healthcare professionals regarding Advance Care Planning in ILwD, particularly those in early-stage dementia (Piers et al., 2018). However, the creation of a program that addresses education for caregivers while their loved one is still in

the early stages, as well as the creation of a space in which ILwD can express their desires regarding their own care, would bridge this gap (Cotter et al., 2017; Piers et al., 2018).

According to the occupational therapy practice guidelines for working with adults with Alzheimer's disease and other related neurocognitive disorders, OTs are qualified to provide early intervention services (The American Occupational Therapy Association, 2017). OTs can create interventions that work to establish, modify, or maintain engagement in meaningful occupations, as well as create environment-based interventions that aim to improve behavior and perception, and reduce the prevalence of falls (The American Occupational Therapy Association, 2017). These interventions have been shown to improve sleep, increase functional mobility within the community, reduce problematic behaviors, and increase the overall QOL of ILwD (The American Occupational Therapy Association, 2017; Prince et al., 2011).

OTs possess the knowledge needed to create educational resources for caregivers. Through caregiver education, OTs are able to improve caregiver QOL, perception of burden, mental health, and self-efficacy (The American Occupational Therapy Association, 2017; Pimouguet et al., 2019). Cognitive reframing techniques, mindfulness and stress reduction interventions, and professionally-led support groups can also enhance caregiver QOL (The American Occupational Therapy Association, 2017; Pimouguet et al., 2019). OTs can work with family members and ILwD by facilitating engagement in meaningful occupations, maintaining routines that support the client's strengths, and modifying activities and environments to increase safety (The American Occupational Therapy Association, 2017). Occupational therapists contribute to successful role-transitioning for caregivers through education on occupational

balance and the expected progression of dementia symptoms (The American Occupational Therapy Association, 2017).

In 2019, researchers conducted the MatheoAlz trial (Maintenance of Occupational Therapy in Alzheimer's disease) in order to assess the impact of occupational therapy on individuals living with dementia (Pimouguet et al., 2019). This trial aimed to determine the impact of an ILwD receiving OT services over four supplementary months, in contrast to receiving routine OT services. The study participants included 240 dyads, or individuals living with dementia and their caregivers. The participants were separated into two groups: control and intervention. The control group was given 12-15 occupational therapy sessions over the course of three to four months. In contrast, the intervention group was given 12-15 occupational therapy sessions, with an additional eight home OT sessions over the course of four supplementary months. It was found that the caregivers who received additional training were better able to transfer their knowledge concerning how to manage and prevent neuropsychiatric behaviors within the individual living with dementia. (Pimouguet et al., 2019). Therefore, occupational therapy practitioners have the skilled knowledge and training needed to educate caregivers on how to better support themselves, as well as their loved ones.

Lifestyle Redesign

Occupational therapists provide assistance with role transitions through preventative lifestyle-based interventions. One effective intervention is the Lifestyle Redesign intervention (Clark et al., 2011). This intervention has proven to be an effective community-based program, for improving the mental, as well as physical health, of older adults (Clark et al., 2011; Cassidy, Richards, & Eakman, 2017; Maeir et al., 2020). This intervention includes: the identification and application of activity modifications, the creation of a plan on how to overcome obstacles when

engaging in activities (i.e., body aches), and the practice of how to engage in one's daily routines while utilizing modifications (Clark et al., 2011). Current research shows that lifestyle-oriented programs can increase mental health, with levels of vitality, social function, and life satisfaction increasing as a result (Clark et al., 2011; Maeir et al., 2020). Furthermore, it was found that the Lifestyle Redesign interventions can improve physical health by lowering levels of perceived bodily pain, and increasing social participation, awareness of community resources, and one's perspective towards the aging process (Clark et al., 2011; Cassidy, Richards, & Eakman, 2017; Maeir et al., 2020). Through implementing programs like these, OTs can provide education and coping strategies to caregivers as they experience their role transition.

Activity Modifications

In order to promote occupational engagement despite the changes associated with the progression of dementia, occupational therapists simplify and modify activities to match the abilities of ILwD. A systematic review titled "Effectiveness of Interventions Designed to Modify the Activity Demands of the Occupations of Self-Care and Leisure for People with Alzheimer's Disease and Related Dementias," discussed the importance of modifying activity demands for ILwD (Padilla, 2011). Activity demands are the specific features within a given activity that influence the amount of effort needed to perform a task (Padilla, 2011; American Occupational Therapy Association, 2017). In order to increase performance, the demands of the activity can be modified to better fit that individual's level of functioning.

Within this systematic review, one study discussed strategies for activity modifications, including: removing unnecessary objects, placing materials in one's line of sight, and simplifying the activity itself (Padilla, 2011). After receiving education on how to simplify task demands, caregivers reported that their loved ones had increased pleasure when engaging in meaningful

activities (Padilla, 2011). An alternative study within this review found that cognitive and behavioral interventions can be used to educate ILwD on how to compensate for their cognitive decline (Padilla, 2011). This study found that compensatory and environmental modifications have the potential to improve an individual's ability to adapt to their environment -- resulting in less caregiver burden (Padilla, 2011).

Early Education for the Caregiver

Early education concerning the progression of dementia can help caregivers feel less apprehensive in caring for their loved one as the ILwD's symptoms progress. Due to a decline in problem-solving abilities, ILwD rely on their caregivers for guidance and support. Therefore, it is essential that caregivers are educated on how to provide the best quality of care for ILwD. The burden of being a caregiver can be reduced by providing education on how to properly care for ILwD. By providing caregivers with education on what the remaining abilities associated with dementia are, as well as how to accommodate them, caregivers are able to experience decreased levels of stress, which then positively impacts their social life and psychological health (Lin et al., 2019). Interventions should be sensitive to the changing needs of caregivers, meaning that the interventions should be client-centered and flexible; interventions will be more successful when they fit the caregiver's needs and take into account the caregiver's own care journey (Lin et al., 2019).

Novice caregivers are those who are new to the role, and as such they are more likely than experienced caregivers to be uneducated or unsure of how to properly provide care to ILwD. Research has shown that novice caregivers are more likely than educated caregivers to institutionalize their loved one living with dementia (Ducharme et al., 2011). This may be due to a lack of knowledge concerning how to care for and manage the cognitive dependencies of a

relative living with dementia (Ducharme et al., 2011). It has been found that when caregivers are given places or people that provide support in behavior management, education, and psychological support, the negative effects of patient symptoms can decrease and the QOL of the caregiver can increase (Lin et al., 2019). Support meetings, educational programs, and practical information on maintaining QOL have been found to be useful. Caregivers should be given information on dementia progression, as well as education on how to change their own point of view, or attitude towards the disease (Lin et al., 2019).

In addition to education regarding how to care for their loved one, caregivers also can benefit from education on how to care for themselves. When caregivers are more occupationally balanced, they experience a decrease in occupational deprivation, which directly correlates with a decrease in the number of healthcare problems and perceived levels of caregiver burnout, and an increase in caregiver QOL and overall happiness (Ducharme et al., 2011; Stockwell, Moyle, Kellett, 2019; Lin et al., 2019). By having a better outlook on their role as a caregiver, caregivers are able to experience increased levels of self-efficacy- confidence in their own abilities- which in turn allows them to provide better care (Lin et al., 2019). Populations that are especially susceptible to experiencing a lack of occupational balance include spouses of ILwD who have no caregiving experience. With occupational imbalance and lack of education, comes increased rates of elder abuse and admittance to inpatient facilities (Ducharme et al., 2011; Tatangelo et al., 2018). However, when caregivers are provided with education and support, both of these statistics have been proven to lower significantly, with more individuals living with dementia being able to age in place (Ducharme et al., 2011; Tatangelo et al., 2018).

One study entitled, “The impact of early psychosocial intervention on self-efficacy of care recipient/carer dyads living with early-stage dementia -- A mixed methods study,” examined

how psychosocial interventions can be beneficial for caregivers and ILwD (Stockwell- Smith et al., 2018). In this mixed methods study, eighty-eight dyads (a caregiver and their loved one) were recruited. The overarching goals of this study were to empower the dyads, establish self-efficacy, give the dyads an opportunity to identify challenges they were experiencing, and subsequently identify support structures that could help them in managing those challenges (Menne & Whitlatch, 2007; Whitlatch, Judge, Zarit, & Femia, 2006; Stockwell- Smith et al., 2018). Dyad members worked collaboratively and individually with a facilitator to identify their current and future care needs, discuss the ILwD's preferences regarding how they would prefer to receive care in the future, and consider suitable care settings (Stockwell- Smith et al., 2018). Three primary domains were addressed in the intervention: self-efficacy, stress from the perspective of dyadic strain, and well-being in relation to QOL and emotional status. Following the study, the majority of the dyads in the intervention group stated that they felt more informed on available support networks after participating in the study (Stockwell- Smith et al., 2018). This study proved that informative and effective interventions can have a positive impact on caregivers' confidence in providing care, as well as the overall relationship between ILwD and their caregivers.

It is essential that caregivers are educated on how to care for themselves, as well as their loved one, before they present with health problems of their own -- or have to reduce their own outside employment or occupational engagement. The amount of time that a caregiver has been in their role should also be taken into consideration when providing caregivers with educational resources -- as it can possibly affect how they view their unmet needs (Lin et al., 2019). It is vital that a proactive approach is taken when treating ILwD. In a proactive intervention approach, caregivers are taught how to adapt to the challenges that come with caring for a loved one living

with dementia, therefore easing the role transition as caregivers move from not being a caregiver, to a part-time or full-time caregiving role (Ducharme et al. 2011).

Some of the main programs that exist regarding caregiver education include: Resources for Enhancing Alzheimer’s Caregiver Health II (REACH II), Savvy Caregiver, Skills2Care, and the Support, Health, Activities, Resources, and Education Program (SHARE) (Weiss et al., 2017; Heid et al., 2019).

Table 3 Existing Programs for Early Intervention

Table 3	Focus of the Program	Program Delivery
REACH II	<p>Designed to help caregivers manage the behaviors of care recipients and to reduce caregiver burden and depression.</p> <p>Includes use of active treatments both in individually in person and over the phone in a group setting, which have been found to be more effective in reducing caregiver burden, with caregivers having better health, sleep quality, physical health, and emotional health following the intervention</p>	<p>REACH II is implemented by trained counselors who observe caregivers and the ILwD in their homes over the course of twelve sessions/six months. Trained professional counselors contact the caregivers via telephone, where they then share their findings, as well as strategies to reduce caregiver burden.</p>
Savvy Caregiver	<p>12-hour course aimed at introducing family caregivers to the caregiving role.</p> <p>Caregivers are educated on the knowledge, skills, and attitudes needed to carry out the caregiving role. Topics that are covered in this program include stress reduction strategies and strategies for caregiver self-care.</p> <p>Found to increase caregiver confidence levels, resulting in a higher QOL.</p>	<p>Savvy Caregiver is conducted by trained caregivers and occupational therapists over the course of six weeks. The content of the program is covered via video training, with all participants having a physical copy of the manual.</p>
Skills2Care	<p>Aims to address the individual and environmental needs of families, with it providing caregivers with the resources</p>	<p>Skills2Care is conducted by an occupational therapist. The OT first observes the context and the</p>

Table 3	Focus of the Program	Program Delivery
	<p>and strategies needed to take care of their loved one</p> <p>Found to increase caregiver knowledge and develop the essential skills needed to successfully care for an ILwD.</p>	<p>environment of the ILwD and their caregiver in their individual setting. Once the home assessment is completed, the OT provides home modification recommendations in order to create a supportive environment for the ILwD.</p>
SHARE	<p>Creates a dialogue between caregivers and councilors (early stage dementia). Topics discussed the future care plan for the ILwD. Protocol makes it possible to create plans of care that accurately reflect the care preferences of both ILwD and their caregivers.</p>	<p>SHARE is implemented in six weekly sessions within the participant's home by a counselor. The sessions are joint sessions between the caregiver and the ILwD, with both parties meeting individually with the counselor.</p>

Note: (Heid et al., 2019; Lykens, Moayad, Biswas, Reyes-Ortiz, & Singh, 2014; Weiss et al., 2017)

Research has shown that REACH II increases the QOL of caregivers, as shown by decreased depression levels, increased self-care and social support, and decreased demonstrated problem behaviors of the ILwD following completion of the program (Weiss et al., 2017). This program provides training for caregivers on how to address problem behaviors that might arise in the later stages of dementia, as well as information on how to improve their own health and safety (Weiss et al., 2017). Similarly, Savvy Caregiver has been found to successfully decrease caregiver depression levels and increase caregiver coping strategies (Weiss et al., 2017).

Skills2Care takes a slightly different approach by educating caregivers on home modifications and skill-building (Weiss et al., 2017). This program has been found to increase caregiver self-care knowledge, as well as caregiver confidence in handling problematic behaviors. SHARE sessions also work to educate caregivers on the skills needed to meet the needs of ILwD (Heid et al. 2019). Through SHARE, individuals living with early-stage dementia are able to work alongside their caregivers to construct a care plan that benefits both of them

(Heid et al. 2019). These resources have helped caregivers to decrease their depression levels, as well as to gain knowledge on how to provide effective care.

Though these programs have been shown to improve the QOL of caregivers, there is a gap in practice concerning a program that addresses all of the topics needed to combat caregiver burnout. The literature indicates that the three main topics to cover within early intervention are: knowledge of remaining abilities, symptom progression, environmental modification, and caregiver health management. Occupational therapists have the training needed to conduct a caregiver and support program that addresses all of the topics stated above, in order to provide caregivers with the education needed to care for their loved one, as well as themselves.

Summary and Conclusions

Research suggests that when caregivers feel more confident in their role, ILwD experience a decrease in elder abuse and institutionalization rates (Ducharme et al., 2011; Tatangelo et al., 2018). Therefore, it is essential for caregivers to understand how early-stage dementia may present in individuals and to find ways in which they can modify given activities to fit the cognitive capacity of their loved one. One of the main gaps that was noted in practice included a lack of early intervention for dementia itself (Bradford et al., 2009; Ducharme et al., 2011). If a diagnosis is not made by a physician, or an individual with dementia is never taken to see a physician, there is a missed opportunity for caregiver early education. It is important that physicians, occupational therapy practitioners, as well as anyone else who is a part of the care team, understand that caregivers may or may not be prepared for their role. Occupational therapy has a place in caregiver education, and though there are existing caregiver programs, there are none that look at the role of caregiving through a holistic, occupational lens. Through an occupational lens, the routines, occupations, rituals, spirituality, beliefs, and roles of the

caregiver are all taken into consideration within the intervention plan (Heid et al., 2019; Lykens et al., 2014; Weiss et al., 2017). Caregivers need to understand and learn how to adjust their routines in order to maintain their own physical and mental health, as well as that of their loved one. This in turn allows them to properly prepare themselves for the role of being a caregiver and to provide optimal care for ILwD (Heid et al., 2019; Lykens et al., 2014; Weiss et al., 2017).

There is a significant need for education, training, and support among the caregiver population for ILwD. While individuals living with early-stage dementia may still be able to function independently in some of their daily activities and occupations, caregivers benefit from education regarding the progression of dementia in order to provide optimal care (Bunn et al., 2012; Alzheimer's Association, 2019). Research has shown how important education on the progression of dementia is, with it being the most effective form of intervention to combat caregiver stress and anxiety (Ducharme et al., 2011). Through educating caregivers on how they can provide effective care to ILwD, their caregiver burnout is likely to decrease, allowing caregivers to feel more confident in their role and provide a higher level of care to their loved one. Additionally, caregivers will then be able to better plan for their loved one's future and become more occupationally balanced in their own daily lives. When caregivers are healthy and happy, they are able to better support their loved ones -- increasing the QOL of everyone involved (Tatangelo et al., 2018). It is vital that caregiver support and education programs be created and implemented early on in order to ensure that caregivers are educated on dementia while their loved one is still in the early stages, allowing time for both caregivers and ILwD to benefit from the education provided through said programs (American Occupational Therapy Association, 2019). Though there are currently few programs that educate caregivers specifically on early-stage dementia, the Early-Bird Caregiver Education Program aims to address this gap in

practice, by supplying OT practitioners with an evidence-based program that addresses early caregiver education. This program is supplemental to existing caregiver programs, and will be used in conjunction with the existing programs in order to better enhance caregiver learning in critical areas that support occupational well-being of the ILwD and the caregiver.

Statement of Purpose

The incidence of dementia continues to rise, with approximately 10 million new cases emerging worldwide each year (World Health Organization, 2020). While important on its own, this statistic fails to encompass the tens of millions of caregivers who provide support to ILwD. It is essential that the caregivers and families of these individuals receive early support; therefore, optimizing the caregivers' and ILwD's physical health, mental health, and overall well-being. Occupational therapists have the training needed to assist caregivers' in their role transition. Through a strength-based model of care, OTs have the skill-set and education needed to successfully identify the strengths, impairments, and functional limitations of ILwD, and subsequently create activity modifications according to these needs (Schaber & Lieberman, 2010; American Occupational Therapy Association, 2019).

While there are currently many caregiver education programs available to those who are caring for an ILwD, there are few that address the specific needs of caregivers of individuals living with early-stage dementia. This project aims to address this gap. Following careful analysis of the literature together with the OT practice framework, program developers were able to determine the most valuable topics to include to support occupational balance within both caregivers and ILwD: remaining abilities within early-stage dementia, activity modification, and caregiver resilience (Heid et al., 2019; Ducharme et al., 2011; Padilla, 2011). In order to best support caregivers of ILwD, it is vital that caregivers are educated on what to expect as their loved one's condition progresses. By providing caregivers with the information they need to be successful in their role, caregivers are more likely to experience a higher QOL, which in turn allows ILwD to be given a higher level of care.

The Early-Bird Caregiver Education Program aims to support OTs providing services to individuals who are new to the caregiving role through the creation of an intervention guide. The program consists of three, forty-minute sessions, all of which will be led by an occupational therapy practitioner. Each session includes its own goals and objectives. By the end of session one, caregivers will be able to understand the behavior, performance patterns, strengths, and remaining abilities of their loved one. Following the completion of session two, caregivers will understand key communication strategies and activity modifications that can be used to improve their daily interactions with their loved one. By the end of session three, caregivers will better value the vital role that they play as a caregiver, understand the importance of their own physical and mental health, and have an increased level of knowledge concerning stress-management and health-management techniques. The aims of this program are for participants to experience decreased levels of stress, increased confidence in their abilities, and have an overall higher QOL.

Though this program was intended to be implemented in the summer of 2020 at the Sonoma County Council on Aging, the pilot sessions were unable to take place due to the restrictions set in place during COVID-19. However, the evidence-based literature that was used in the creation of the Early-Bird Caregiver Education Program was utilized to inspire a 12 week, level two fieldwork opportunity. Although the OT fieldwork students provided individual rather than group interventions, the feedback from the OT service recipient indicated that the topics addressed in the program are of value to caregivers of ILwD. The Early-Bird Caregiver Education Program addresses needs that are experienced by millions of caregivers worldwide, offering caregivers the education needed to support their QOL, as well as the QOL of the ILwD.

Theoretical Framework

Through the utilization of the strengths and remaining abilities of ILwD, occupational therapists can have a positive impact on the lives of ILwD and their caregivers. This project will utilize three theoretical frameworks: The General Stress Process Model, The Cognitive Disabilities Model, and the Kawa River Model.

The General Stress Process Model

The General Stress Process Model focuses on four factors that contribute to stress: caregiving context, primary stressors, secondary stressors, and potential mediators (Pearlin, Mullan, Semple, & Skaff, 1990). Primary stressors are described as cognitive impairments and problematic behaviors (Pearlin et al., 1990). As a result, caregivers can develop subsequent secondary stressors, such as familial strain (Pearlin et al., 1990). When caregivers experience a large amount of stress, their family members can undergo an increase in stress levels as well. By proactively identifying the potential stressors that caregivers face, they are given the opportunity to physically and mentally prepare for the obstacles to come. As a result, they are then able to improve their mental health, as they feel more confident in their ability to endure and continue providing quality care to their loved one. A study conducted by Ostwald, Hepburn, & Burns (2003), looked at caregiver education for loved ones with dementia. Ninety-four families (including the primary caregiver) and the individual with dementia, completed seven weekly workshop sessions (Ostwald, Hepburn, & Burns, 2003). Utilizing this model as their theoretical framework for the program, they concluded that the QOL of caregivers was dependent on the resources that caregivers have, including family and formal services and the caregiver's knowledge, skill, outlook, and ability to handle various situations (Ostwald et al., 2003). This model informed the development of this project, as its focus is on the stressors that contribute to

caregiving for ILwD. Educating caregivers and providing tools on how to best support their loved one, results in caregivers feeling more prepared and better able to meet the needs of ILwD.

Cognitive Disabilities Model

The Cognitive Disabilities Model (CDM) integrates functional cognition with the level of occupational performance that an individual is capable of (Allen, 1992). In order to define the level of cognitive functioning, this model utilizes an ordinal and hierarchical scale of six functional cognitive levels: automatic actions, postural actions, manual actions, goal-directed actions, exploratory actions, and planned actions (Allen, 1992). Once the level of cognition has been determined, task and activity analysis are conducted in order to ensure that the chosen tasks match the cognitive abilities of each individual (Allen, 1992). When implementing interventions centered around the CDM, caregivers are encouraged to focus on their loved one's needs, as well as to implement task modifications that grade-down activity demands in order to meet the cognitive capacity of ILwD. In order to do so, it is essential that caregivers understand the signs and symptoms of early-stage dementia in order to effectively adapt activities and occupations to fit the ILwD's daily needs (Cotter et al., 2017). The ultimate goal of this model is to maintain the existing skills of the participants and to develop coping strategies that can be used in daily life (Allen, 1992). This model applies to this project because it specifically addresses task modification and education concerning remaining abilities, both of which are addressed through this project. The OT practitioner will provide information regarding predicted learning, problem solving, and decision making abilities during the early stages of dementia, as well as how to adapt activities and environments in order fit the predicted remaining abilities of the ILwD.

The KAWA River Model

The KAWA River Model provides a framework for occupational therapy practitioners to assist individuals in understanding the supports and barriers within their own lives. The river represents an individual's "life flow and overall occupations." The contextual and environmental factors are classified as the riverbank, factors that block engagement in occupation are the rocks (or Iwa), and client factors and resources that can support or hinder occupations are driftwood (or Ryubohu) (Teoh & Iwama, 2016). The idea of the river centers around one's life flowing through the riverbanks and reaching obstacles that block its flow (the rocks). In order to keep going, one must find a way to navigate through the rocks and locate a gap (or Sukima) so that his or her lifeflow can continue flowing (Iwama, 2006). The driftwood and riverbank can have one of two purposes -- they can either support or hinder one's life flow (Iwama, 2006). This model allows caregivers to visually identify and analyze what supports they have and what barriers are currently contributing to their own occupational imbalance. By allowing caregivers to select their own quantifiers for "supports" and "barriers," they will be able to define their own perceptions of what is contributing to their success, or lack thereof, in their caregiving role. The Kawa River Model will be used during session three of the Early-Bird Caregiver Education Program. During this session, participants will be able to identify the factors in their own lives that they perceive to be "supports" and "barriers", as well as create a plan concerning how to navigate through their "rocks" in order to keep their "lifeflow" flowing.

Ethical and Legal Considerations

In order to maintain ethical and legal considerations, program developers will have all participants sign a consent form (Appendix A) prior to the start of the educational sessions. This waiver will include confidentiality regarding information shared between the participants, and any personal information shared between the OT and the participants. Any health information that is disclosed to the occupational therapy practitioner who is facilitating the program should remain confidential in order to avoid a violation of the HIPAA Privacy Rule. Under this rule, patient authorization would need to be obtained in order for any personal health information to be disclosed. By signing the confidentiality waiver, participants will be providing consent for participation and acknowledging that they are free to leave the program at any time. Legal considerations were also taken into account, with the program developers obtaining permission to use copyrighted materials, including the Kingston Caregiver Stress Scale (Appendix B).

This project has the potential to increase the autonomy of ILwD. Through educating caregivers on how to best support their loved one's needs, they will simultaneously be learning how to increase the ILwD's autonomy. Program developers will take additional considerations regarding how to retain autonomy, due to the caregivers being the ones speaking on behalf of the ILwD (The American Occupational Therapy Association, 2020). The dilemma between encouraging caregivers to take better care of themselves and devoting their time and energy to the needs of the ILwD is also relevant, since additional education may increase the QOL of the caregiver, but, as a result, cause less focus or attention to be given to the ILwD. The program should be properly presented, and participants should be fully informed of what the program entails before they agree to participate. In regard to nonmaleficence, this project should not increase caregiver burden or worsen the QOL of either the caregiver or the ILwD (The American

Occupational Therapy Association, 2020). The program developers will take careful consideration to avoid overwhelming the participants with information and will not provide them with false information that could result in additional caregiver burden.

In order to maintain veracity, the program developers will ensure that only accurate and reliable information is given to the caregivers (The American Occupational Therapy Association, 2020). Furthermore, the OT assigned to leading the caregiver sessions will offer only education and training that he or she is qualified for. As a matter of justice, the OT will work to help those in need of OT services -- such as ILwD and their caregivers. In this project, this is done through the creation of a caregiver educational program for early-stage dementia. This project also addresses justice by working to provide caregivers with the resources needed to decrease their experienced occupational deprivation (The American Occupational Therapy Association, 2020).

Methodology

Agency

This program will be made available for occupational therapy practitioners on the Dominican University of California Healthy-Aging website. The program was intended to be piloted by Gina Tucker-Roghi, assistant professor at Dominican University of California, in the summer of 2020 at the Sonoma County Council on Aging. The Sonoma County Council on Aging strives to make recommendations regarding the needs of older and disabled adults, as well as their caregivers (County of Sonoma, 2020). In order to follow the restrictions put in place due to COVID-19, program developers created an adapted version of the pilot program. Caregivers were provided with services consistent with the program interventions in an individualized, one-on-one format, rather than in a group. In an effort to meet the COVID- 19 protocols, the pilot was implemented via telehealth and the program was adapted in order to be compatible in an online format.

Target Population

This project will address individuals who are caring for someone that is living with early-stage dementia and their caregivers through the Sonoma County Council on Aging. Participants will include caregivers of the members of the adult day program who are experiencing early-stage dementia, memory loss, or other cognitive impairments. The target population will also include occupational therapy practitioners, who will implement the Early-Bird Caregiver Education Program intervention guide.

Project Design

The project design includes three sessions that can be utilized when hosting a virtual workshop for caregivers of ILwD. These sessions will be conducted in a group instead of

individualized level interventions. Group interventions will allow caregivers to develop rapport with other caregivers; therefore, providing them with another support system.

After analyzing existing programs, program developers identified four key topics that were covered throughout the programs, yet not all present in one, comprehensive program. These programs addressed: behaviors associated with early stage dementia, environmental modifications, caregiver burnout and the dyadic relationship between the caregiver and the ILwD. Program developers created sessions and an intervention guide that addressed these key topics all together. The guide clearly outlines the information that should be covered in each session, a materials list for each session, and various informative handouts. The overall goal of the program is to support occupational therapy practitioners in training caregivers through the creation of an intervention guide. Furthermore, the goal of the three sessions is to support the caregivers of ILwD, with the caregivers being educated on what the remaining abilities of ILwD are, how to modify activities when interacting with ILwD, and how to manage their own occupational balance.

Each of the three sessions will last approximately forty minutes long, with each session being led by an occupational therapy practitioner. The purpose of session one is to educate caregivers on the signs, symptoms, and remaining abilities within early-stage dementia (Appendix C). Through an interactive PowerPoint presentation and group discussion, caregivers will demonstrate an understanding of the behavior, performance patterns, strengths, and remaining abilities of ILwD.

In session two, caregivers will be educated on activity modification, and will be given the opportunity to grade an activity up and down in order to fit the expected remaining abilities of their loved one (Appendix C). This session will be more hands-on, and will involve the

interaction of multiple caregivers, with them working in pairs to create solutions regarding how to engage their loved ones in occupation. By the end of session two, caregivers will better understand key skills and communication strategies when working with ILwD, as well as how to modify activities and environments in order to fit the needs of their loved ones.

The third session will focus on education concerning caregiver burnout and occupational balance (Appendix C). The occupational therapist will utilize the KAWA River model to assist caregivers in identifying barriers they face that contribute to burnout. In contrast, they will also identify what support systems can help them as a caregiver. The occupational therapist will then share information regarding caregiver burden, emphasize occupational balance, as well as key strategies that can be used in combating occupational deprivation. Caregivers will have the opportunity to use the session as a support group and will be able to share what they struggle with, as well as what strategies they have found to be effective. By the end of session three, caregivers will identify barriers to their own well-being; demonstrate an increased understanding in the value of being a caregiver, the importance of maintaining their own physical and mental health, and how to utilize stress management and health management techniques. Due to this program being offered in a virtual format, it can be applied in a variety of settings including community-based organizations, support groups, and/or as an educational offering in a medical setting.

Project Development

In developing the project, the program developers analyzed alternative caregiver and LifeStyle Redesign programs from an occupational perspective. This was done in order to determine what components of existing caregiver programs would be relevant to OT practice for caregivers of an ILwD, as well as which components were lacking in existing programs. The

programs that were analyzed include: REACH II, Savvy Caregiver, Skills2Care, and SHARE. Through analyzing these programs, the program developers were able to identify a gap in practice and create a program that addressed the missing components.

In order to create the intervention guide, the program developers used a platform called Rise. This platform was chosen in order to allow the program developers to share the educational materials in a technological format. When creating the project, program developers also conducted a needs assessment in order to better understand the educational needs of caregivers of ILwD. In doing so, the program developers met with leaders at Whistlestop, a community-based organization in San Rafael, California that aims to support the independence and overall QOL of older adults and those living with disabilities within Marin County, California. Through meeting with this organization, the program developers were better able to understand the concerns and needs of older adults who are beginning to experience memory loss.

Project Implementation Plan

The implementation guide will be available on the DUC Healthy Aging website and will detail the materials that should be utilized during the three sessions, as well as specific instructions on how to facilitate the sessions. This implementation guide will be on a public domain and will be accessible to all occupational therapy practitioners. The program will educate caregivers on what to expect in the coming stages of dementia, inform caregivers on how to adapt to changes in the remaining abilities of their loved ones, provide caregivers with stress-reducing strategies, and teach the skills needed to maintain occupational balance while simultaneously caring for someone else. When an occupational therapist is able to implement our program as the program developers originally intended, the implementation guide provided on

the DUC Healthy Aging website will serve as guidance regarding how to implement the sessions in a group setting.

Due to the restrictions set in place regarding COVID-19, this project was unable to be piloted in the summer of 2020 at the Sonoma County Council on Aging. Though this specific program was unable to be implemented, the evidence-based findings that underlie the Early-Bird Caregiver Education Program were able to be used to inspire a level II fieldwork opportunity for Dominican University of California occupational therapy (OT) students. Under the supervision of Dominican University of California faculty, four graduate occupational therapy students were able to conduct one-on-one sessions with ILwD and their caregivers. Upon the completion of their fieldwork experience, program developers asked the OT fieldwork students to complete a survey addressing the projected value of the Early-Bird Caregiver Education Program for the caregiver population.

Project Evaluation

During the beginning of the first session, participants will be given the Kingston Caregiver Stress Scale (Appendix B) in order to assess their current stress levels, as well as factors that are contributing to their stress. This assessment will provide baseline data and will indicate the current level of stress that the caregivers are experiencing. At the end of session three, participants will complete the KCSS again in order to assess if there was a change in their stress levels. The participants will be asked to complete the KCSS again six weeks after the completion of session three, to determine whether or not the caregiver education program was significantly impactful in decreasing the caregivers' stress levels. The caregivers will also be asked to complete a feedback form after the completion of session three (Appendix D). Within this form, caregivers will be asked to provide feedback regarding which parts of the program

were effective and which parts need improvement. The participants will answer each question on a sliding scale, with one being “not effective at all” and five being “extremely effective.” There will be a short-answer opportunity after each question, where the caregivers will be able to expand on why they chose the score that they did. In order to assess the effectiveness of the virtual training manual, the occupational therapist in charge of leading the virtual sessions will be asked to provide feedback using a similar sliding scale, and short-answer questionnaire (Appendix E). All feedback will be taken into consideration, and appropriate changes will be made following the initial program implementation.

Though the Early-Bird Caregiver Education Program was unable to be implemented in a group setting due to the COVID-19 restrictions, program developers were able to conduct a survey and collect data on the potential value of the program (Appendix F). In order to do so, the four graduate occupational therapy fieldwork students who participated in the level II fieldwork experience were asked to complete a survey addressing the projected value of our program for the targeted population. The students reported that they worked one-on-one with three to four caregivers, whose ages fell between forty and seventy or more years old. In regard to which areas of education they found the most important to cover, the students cited caregiver knowledge, caregiver skills, caregiver burnout and resilience, and community resources. They found that caregivers were interested in learning effective communication strategies, activity modifications, environmental modifications, and caregiver resilience. The students also reported limitations to providing caregiver support online: physical limitations, inability of caregivers to implement environmental modifications due to social distancing, and exacerbation of caregiver burnout symptoms due to social isolation, occupational deprivation, and the home environment due to COVID-19. The results of this survey show that the material covered in the Early-Bird Caregiver

Education program are of value; therefore, supporting the validity of this program. Although the OT services provided by the fieldwork students were conducted in one-on-one virtual and socially distanced sessions, the Early Bird Caregiver program is intended to be done in group, in-person sessions. The results from the survey indicate that the topics covered in this program are meaningful. When this program is able to be implemented post COVID-19, the topics discussed above are all areas of education and training that are included in the program.

Figure 1 Survey Results: Most important topics to address in intervention

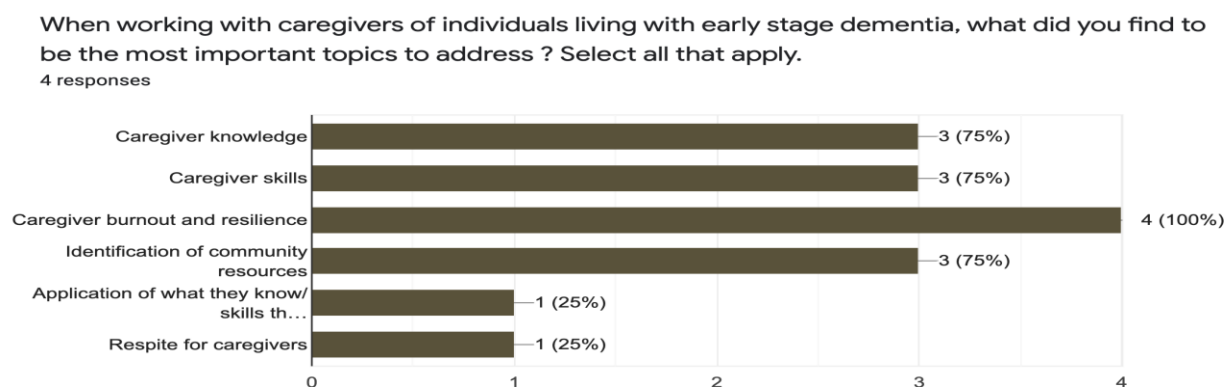


Figure 2 Survey Results: Frequency of interventions

How often did you provide education and training on the following topics in your intervention?

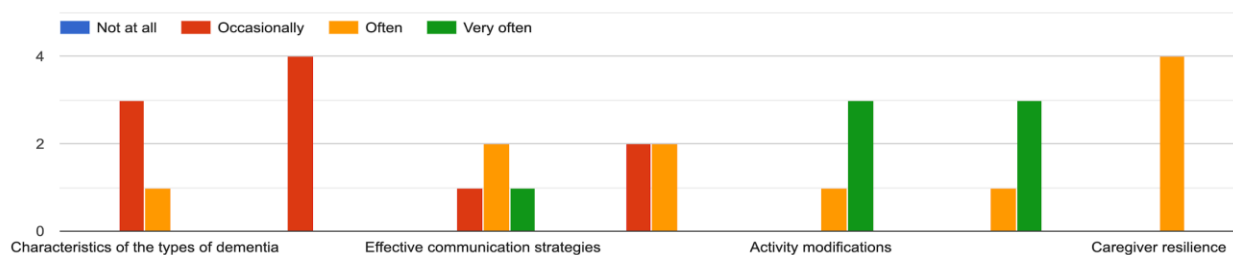
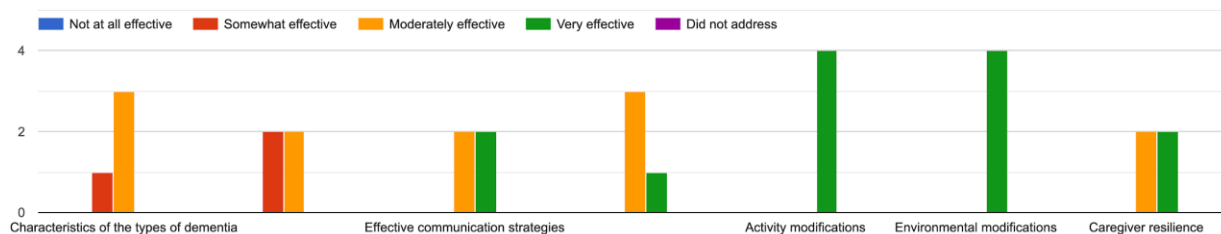


Figure 3 Survey Results: Effectiveness of interventions

When implementing these interventions, how effective were they in supporting the caregivers ?



Program limitations include the inability of the program to be implemented due to COVID-19. Though program developers were able to gather feedback regarding the possible value of the Early-Bird Caregiver Education program, no official results or findings were able to be gathered. It is the program developers' hope that this program will be built upon by the next class of Dominican University of California graduate occupational therapy students, and that the program will eventually be implemented in a functional format.

Discussion, Summary, and Recommendations

This project aims to create an early intervention program that will increase the QOL of both caregivers and their loved ones living with early-stage dementia. Dementia affects not only cognition and memory, but also one's well-being. In order to support their loved one, it is essential that caregivers be educated on the signs and symptoms of dementia, so that they can be prepared as the symptoms of dementia progress (Cotter et al., 2017). By providing caregivers the necessary education on how to identify the remaining abilities of their loved one, utilize activity modification, and support their own well-being, caregivers will be able to support their loved one to the best of their ability (Schaber & Lieberman, 2010; American Occupational Therapy Association, 2019).

Current practice lacks educational programs focused specifically on supporting caregivers of individuals living with early-stage dementia. However, this project aims to address this gap. The intervention guide and three virtual sessions detailed in this project can be utilized by OT practitioners in order to address the needs of caregivers who are currently, or will be, caring for someone who is living with early-stage dementia. This project has the capacity to increase the knowledge and capabilities of caregivers, which in turn has the potential to increase the QOL for caregivers and ILwD. When these interventions are implemented early on in the dementia progression, they have the potential to make a significant impact on both caregivers and ILwD.

This project's focus on activity modification and lifestyle management will provide caregivers with information on how they can support their loved one's occupational engagement, as well as their own. A decrease in occupational deprivation opens the door for improvements in other areas, such as physical, emotional, and social health. Early intervention can increase the QOL of caregivers and ILwD and decrease the rates of elder abuse and admittance to inpatient facilities -- allowing more individuals living with dementia to age in place (Ducharme et al., 2011; Tatangelo et al., 2018).

Occupational therapy has a distinct role in caregiver education, and though there are existing caregiver programs, there are few that look at the role of caregiving from an occupational lens. OTs have the skilled training needed to assess and determine the cognitive awareness, gross motor movements, and manual actions associated with the various stages of dementia (Allen, 1991). OTs also have training needed to take the information gained from their observations and use it to determine how an ILwD's occupational performance will likely be impacted. Under the guidance of an occupational therapy practitioner, caregivers will benefit

from education on how to adapt activities, adjust their routines, acclimate to a new role, and maintain their own physical and mental health (The American Occupational Therapy Association, 2017; Pimouguet et al., 2019). By providing OTs with an evidence-based resource to support group interventions for caregivers of ILwD, they will be able to provide effective and valuable services that have the potential to improve the QOL of caregivers. With early assessment and intervention comes an opportunity for early education. When caregivers and ILwD are informed of the expected symptoms and best care practices, ILwD have a better chance of maintaining their highest level of functioning regarding everyday activities.

Though this program was unable to be implemented due to COVID-19, program developers were able to receive feedback from Dominican University of California graduate occupational therapy students who participated in a level II OT fieldwork experience inspired by our program. Following the completion of their fieldwork, these same students completed a survey addressing the projected relevance of our program for caregivers of ILwD (Appendix F). The students reported that the caregivers they served fell between the ages of forty to seventy or more years old. During their one-on-one sessions, they found the following topics the most important to cover: caregiver knowledge, caregiver skills, caregiver burnout and resilience, and community resources.

The results of this survey support the validity of the topics included in the Early-Bird Caregiver Education Program. Though the fieldwork experience was done one-on-one and was led by occupational therapy students- our program is intended to be implemented in a group by an occupational therapy practitioner- the survey results showed that the topics addressed in this program are meaningful. When this program is able to be implemented post COVID-19, the

topics discussed above are all areas of education and training that will be included in the Early-Bird Caregiver Education program.

In regard to program limitations, the Early-Bird Caregiver Education Program consists of only three sessions. Due to the program length lasting a month, it is feasible to assume that three sessions are not long enough to develop rapport with caregivers. Furthermore, this program is meant to be implemented in a group setting, which inadvertently makes it less client-centered. If the sessions were created to be one-on-one sessions, it is plausible that the caregivers would receive more individualized and personalized care. The survey conducted with the occupational therapy graduate students, showed that the caregiver services included in this program are valuable in one-on-one sessions. However, program developers were unable to assess if these same services would be just as valuable in a group setting. Furthermore, due to COVID-19 restrictions, the program had to be altered in order to be offerable on a virtual platform; the instruction manual was adapted in order to accommodate the social distancing guidelines. It is possible that the effectiveness of the program will be lowered when implemented through a virtual format, in contrast to an in-person setting.

Further action regarding the program could include adding education concerning self-care, stress management, and occupational engagement during COVID-19 restrictions. Due to many caregivers and ILwD being classified as part of the “at-risk group” for developing COVID-19, education could be provided on how to maintain one’s physical, cognitive, and psychological health, while simultaneously sheltering-in-place. Virtual forms of community support are incredibly valuable during COVID-19, with this program having the potential to increase the health, well-being, and occupational balance of caregivers and ILwD both during, and well beyond, the restrictions of COVID-19.

Occupational therapy has a significant role in caregiver education. However, there are few existing early education programs that look at the role of caregiving through an occupational lens. Through caregiver education on how to identify remaining abilities and modify activities for ILwD, and caregiver support to adjust their own routines in order to maintain their physical and mental health, caregivers will be more prepared to provide optimal care to their loved one living with dementia.

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Appendix A: Consent form

**CONSENT FORM TO BE A RESEARCH PARTICIPANT DOMINICAN UNIVERSITY
OF CALIFORNIA**

1. I understand that I am being asked to participate as a Participant in a research study designed to assess whether participation in a caregiver education program has a positive effect on the overall quality of life of caregivers of individuals living with early-stage dementia, memory loss, or other neurocognitive impairments. This research is part of Brock Albee, Mia Lopez, and Tyler Tree's Student Senior Thesis research project at Dominican University of California, California. This research project is being supervised by Gina Tucker-Roghi, PhD, OTR/L, Occupational Therapy Department, Dominican University of California.
2. I understand that participation in this research will involve taking part in three virtual sessions, with each lasting approximately forty- minutes long.
3. I understand that my participation in this study is completely voluntary, and I am free to withdraw my participation at any time.
4. I understand that disclosed information will be kept confidential. All information shared amongst study participants and between the study participants and the occupational therapy practitioner will not be discussed with outside personnel.
5. 5. I understand that by participating in this study, I am contributing to the development of a quality caregiver education program concerning early-stage dementia care. I may experience improved behavior, occupational balance, and quality of life when performing meaningful occupations. I may also experience increased stress and caregiver burden.

6. I understand that my participation involves no physical risk, however, if I experience any problems or serious distress due to my participation, I am free to withdraw from the study. The researchers may be contacted at mia.lopez@students.dominican.edu.
7. All procedures related to this research project have been satisfactorily explained to me prior to my voluntary election to participate.
8. I understand that if I have any further questions about the study, I may contact the researchers at mia.lopez@students.dominican.edu. If I have further questions or comments about participation in this study, I may contact the Dominican University of California Institutional Review Board for the Protection of Human Participants (IRBPHP), which is concerned with the protection of volunteers in research projects. I may reach the IRBPHP Office by calling (415) 482-3547 and leaving a voicemail message, by FAX at (415) 257-0165 or by writing to the IRBPHP, Office of the Associate Vice President for Academic Affairs, Dominican University of California, 50 Acacia Avenue, San Rafael, CA 94901.

I HAVE READ AND UNDERSTAND ALL OF THE ABOVE EXPLANATION REGARDING THIS STUDY. I VOLUNTARILY GIVE MY CONSENT TO PARTICIPATE. A COPY OF THIS FORM HAS BEEN GIVEN TO ME FOR MY FUTURE REFERENCE.

Signature

Date

Appendix B: Kingston Caregiver Stress Scale

Kingston Caregiver Stress Scale (KCSS)

Patient Name: _____ Case #: _____

Caregiver: _____ Relation to Patient _____ Date: _____



Lives in: Community ___ Long Term Care Facility ___ Other ___

Some people report feelings of stress surrounding certain aspects of care giving. To what extent, if any, do these apply to you in your role of care giving to your spouse or relative? Using a 5 point rating scale, where 1 equals no stress and 5 equals extreme stress, indicate the extent of the stress or frustration you feel surrounding the following issues.

1	2	3	4	5
Feeling NO Stress (Coping fine, no problems)	Some Stress	Moderate Stress	A lot of Stress	Extreme Stress (Feeling at "end of rope", health at risk)

CARE GIVING ISSUES					
TO WHAT EXTENT...					
1	Are you having feelings of being overwhelmed, over worked, and/or over burdened?	1	2	3	4 5
2	Has there been a change in your relationship with your spouse/relative?	1	2	3	4 5
3	Have you noticed any changes in your social life?	1	2	3	4 5
4	Are you having any conflicts with your previous daily commitments (work/volunteering)?	1	2	3	4 5
5	Do you have feelings of being confined or trapped by the responsibilities or demands of care giving?	1	2	3	4 5
6	Do you ever have feelings related to a lack of confidence in your ability to provide care?	1	2	3	4 5
7	Do you have concerns regarding the future care needs of your spouse/relative?	1	2	3	4 5


FAMILY ISSUES					
TO WHAT EXTENT...					
8	Are you having any conflicts within your family over care decisions?	1	2	3	4 5
9	Are you having any conflicts within your family over the amount of support you are receiving in providing care?	1	2	3	4 5

FINANCIAL ISSUES					
TO WHAT EXTENT...					
10	Are you having any financial difficulties associated with care giving?	1	2	3	4 5

This form should be used in conjunction with the **KCSS Administration and Interpretation Manual** which can be freely downloaded from: www.kingstonscales.ca or email: kscales@queensu.ca

Appendix C: Session Flyers

Session One



DOMINICAN UNIVERSITY OF CA

EARLY-BIRD CAREGIVER EDUCATION PROGRAM

A program to support caregivers of individuals with early-stage dementia or memory loss or other cognitive impairments

SESSION 1

Are you unsure of how to care for someone with memory loss? Does your loved one's behavior confuse you? Do you no longer know how to talk to your loved one? Are you concerned about how your loved one's condition will progress? Join our session to learn more!

Session Two



DOMINICAN UNIVERSITY OF CA

EARLY-BIRD CAREGIVER EDUCATION PROGRAM

A program to support caregivers of individuals with early-stage dementia or memory loss or other cognitive impairments

SESSION 2

Does your loved one struggle to complete tasks they once knew how to do? Are you unsure of how to support them? Join our session and learn more!



Session 3



DOMINICAN UNIVERSITY OF CA

EARLY-BIRD CAREGIVER EDUCATION PROGRAM

A program to support caregivers of individuals with early-stage dementia or memory loss or other cognitive impairments

SESSION 3

Do you feel overwhelmed or stressed?
Have you noticed a decrease in your physical or mental health? Do you no longer have the time to engage in activities that are meaningful to you? Join our session to learn how you can best support yourself!



Appendix D: Program participant feedback form

Early-Bird Caregiver Education Feedback Form

Your feedback is important to us! Please complete the evaluation below, any and all feedback given will be taken into consideration. The questionnaire requires approximately fifteen minutes of your time and will assist us in bettering our program for the future. If you have any questions, comments or concerns, please contact us at mia.lopez@students.dominican.edu Thank you for your time!

Brock Albee, OTS

Mia Lopez, OTS

Tyler Trees, OTS

Please state your first and last name *

Your answer

The program leader *

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
Was well prepared					
Led an informative class					
Explained the topics well					
Taught at an appropriate pace					
Was receptive to the participant's questions					
Stimulated interest in the sessions					
Stimulated me to think and learn					
Developed good rapport with the class					
Provided opportunities for discussion					

If you answered, "strongly disagree," "disagree," or "neither agree nor disagree" to any of the questions above, can you please expand on your reasoning? If this does not apply to you, please simply write "N/A." *

Your answer

The program *

	Strongly Disagree	Disagree	Neither disagree nor agree	Agree	Strongly Agree
Addressed the stated objectives					
Presented information without personal bias					
Included professional and clear supportive materials					
Met my expectations and objectives for participating in this program					

If you answered, "strongly disagree," "disagree," or "neither agree nor disagree" to any of the questions above, can you please expand on your reasoning? If this does not apply to you, please simply write "N/A." *

Your answer

How effective was the program in educating you on *

	Not at all effective	Somewhat effective	Moderately effective	Very effective	Did not address
Remaining abilities and strengths of your loved one					
Communication strategies					
Activity modifications					
Environmental modifications					
Community resources					

Caregiver stress management techniques					
Caregiver health management techniques					

If you answered, "not at all affective," "somewhat effective," or "moderately effective" to any of the questions above, can you please expand on your reasoning? If this does not apply to you, please simply write "N/A." *

Your answer

What is your overall satisfaction with the program? *

Not at all satisfied

Very Satisfied

1	2	3	4	5

Is there any additional information that you wish had been included in the program? *

Your answer

Appendix E: Occupational therapy practitioner feedback form

Early-Bird Caregiver Education Feedback Form

Your feedback is important to us! Please complete the evaluation below, any and all feedback given will be taken into consideration. The questionnaire requires approximately fifteen to twenty minutes of your time and will assist us in bettering our program for the future. Please share your experiences for each session and share any feedback you have on the effectiveness of the intervention guide for you as an OT practitioner. If you have any questions, comments or concerns, please contact us at mia.lopez@students.dominican.edu Thank you for your time!

Brock Albee, OTS

Mia Lopez, OTS

Tyler Trees, OTS

Please state your first and last name *

Your answer

Session One

Mark only one oval per row

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Adequately addressed remaining abilities					
Adequately addressed performance patterns					
Give participants ample time to ask questions					
Encouraged participant participation					

Allowed a sufficient amount of time to cover the program materials					
Instructions and handouts were clear and professional					
A virtual platform was effective for presenting the material					

If you answered, “strongly disagree,” “disagree,” or “neither agree nor disagree” to any of the questions above, can you please expand on your reasoning? If this does not apply to you, please simply write “N/A.”

Your answer

Did you experience any difficulties implementing session one? What were the barriers you encountered? Did the virtual format pose any challenges?

Your answer

What went well within session one? What information were the participants most receptive to?

Your answer

Overall, how satisfied were you with session one?

Mark only one oval

Not at all satisfied

Very Satisfied

1	2	3	4	5

Session two

Mark only one oval per row

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Provided useful information on communication strategies					
Provided useful information on activity modifications					
Provided useful information on environmental modifications					
Gave participants ample time to answer questions					
Encouraged participant participation					

Allotted a sufficient amount of time to cover the program materials					
Included clear instructions/handouts and presented the information in a professional manner					

If you answered, “strongly disagree,” “disagree,” or “neither agree nor disagree” to any of the questions above, can you please expand on your reasoning? If this does not apply to you, please simply write “N/A.”

Your answer

Did you experience any difficulties implementing session two? What were the barriers you encountered? Did the virtual format pose any challenges?

Your answer

What went well within session two? What information were the participants most receptive to?

Your answer

Overall, how satisfied were you with session two?

Mark only one oval.

Not at all satisfied

Very Satisfied

1	2	3	4	5

Session three

Mark only one oval per row.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Provided useful caregiver stress management techniques					
Provided useful caregiver health management techniques					
Provided useful community resources					
Gave participants ample time to ask questions					
Encouraged participant participation					
Allotted a sufficient amount of time to cover the program materials					

Included clear instructions/handouts and presented the information in a professional manner					
---	--	--	--	--	--

If you answered, “strongly disagree,” “disagree,” or “neither agree nor disagree” to any of the questions above, can you please expand on your reasoning? If this does not apply to you, please simply write “N/A.”

Your answer

Did you experience any difficulties implementing session three? What were the barriers you encountered? Did the virtual format pose any challenges?

Your answer

What went well within session three? What information were the participants most receptive to?

Your answer

Overall, how satisfied were you with session three?

Mark only one oval.

Not at all satisfied

Very Satisfied

1	2	3	4	5

Do you have any additional comments or suggestions in regard to this program’s development?

Your answer

Appendix F: Occupational therapy students survey

Early Education for Caregivers Survey

Hello! For our capstone project, we are creating a program to support caregivers of those living with early-stage dementia. Our program will include three sessions, with the topics including education on early-stage dementia, education on the course of dementia, activity modification, and caregiver resilience. We are curious as to what topics you found helpful to discuss when completing your fieldwork over the summer, and we would appreciate any feedback or advice that you have after working to support the caregivers. Thank you for your time!

Brock Albee, OTS

Mia Lopez, OTS

Tyler Trees, OTS

* Required

Email address *

Your email

How many caregivers did you serve? *

1	2	3	4	5	6	7	8

What was the age range of the caregivers? *

	0	1-2	3-4
20-30 years old			
30-40 years old			
50-60 years old			
60-70 years old			
70+ years old			

When working with caregivers of individuals living with early stage dementia, what did you find to be the most important topics to address ? Select all that apply. *

	Caregiver knowledge
	Caregiver skills
	Caregiver burnout and resilience
	Identification of community recourses
	Other:

How often did you provide education and training on the following topics in your intervention? *

	Not at all	Occasionally	Often	Very Often
Characteristics of the types of dementia				
Stages / Progression of dementia				
Effective communication strategies				
Behavior characteristics				
Activity modifications				
Environmental modifications				
Caregiver resilience				

When implementing these interventions, how effective were they in supporting the caregivers ?

*

	Not at all effective	Somewhat effective	Moderately effective	Very effective	Did not address
Characteristics of the types of dementia					
Stages / Progression of dementia					
Effective communication strategies					
Behavior characteristics					
Activity modifications					
Environmental modifications					
Caregiver resilience					

Did you experience any difficulties implementing planned interventions? What were the barriers you encountered? What resources would have helped you as a clinician in providing these interventions?

Your answer

Where there any additional topics that caregivers expressed an interest in learning?

Your answer