

AN OCCUPATIONAL THERAPY PERSPECTIVE: UNDERSTANDING THE
EMOTIONAL, SOCIAL, AND SUPPORT NEEDS OF CAREGIVERS OF PATIENTS
WITH ALZHEIMER'S DISEASE

A Thesis submitted to the faculty at Stanbridge University in partial fulfillment of the
requirement for the degree of Master of Science in Occupational Therapy

by

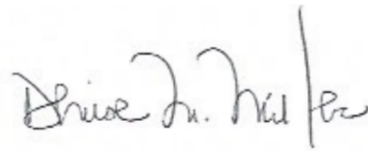
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Certification of Approval

I certify that I have read *An Occupational Therapy Perspective: Understanding the Emotional, Social, and Support Needs of Caregivers of Patients with Alzheimer's* by Natasha Florez, Alexander Mauter, Xylie Parker, and Anthony Valencia, and in my opinion, this work meets the criteria for approving a thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy at Stanbridge University.



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Abstract

Alzheimer's disease (AD) is the most common form of dementia, accounting for 60-80% of cases. AD leads to a progressive loss in cognition, behavior, and overall functional capabilities, and there is no current cure. With age being the greatest known risk factor and the number of older Americans growing rapidly, the number of new and existing cases of AD in the United States will rise exponentially from 5 million to 14 million living with AD in the next few decades. Currently, 83% of caregivers for AD patients are unpaid family members or friends that have not received adequate training or resources to provide the support required. These caregivers experience substantial health complications caused by the emotional, physical, social, and financial burdens of caregiving, all of which can lead to a decreased quality of life. Caregivers of AD experience over twice the amount of depression, anxiety, and stress as non-caregivers. The design of this study focused on a mixed-methods cognitive behavioral therapy-based needs assessment to understand the emotional, social, and support needs of caregivers of AD. The findings and results of this study indicate that occupational therapists will be able to identify and address caregiver emotional, social, and support needs through the use of this needs assessment.

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An Occupational Therapy Perspective: Understanding the Emotional, Social and Support
Needs of Caregivers of Patients with Alzheimer's Disease

Alzheimer's disease (AD) is the sixth leading cause of death in the United States. Aging is the greatest known risk factor, as AD most commonly affects people aged 65 and older (Bowen, Gonzalez, Edwards, & Lippa, 2014). AD is a specific type of dementia that is known for the progressive loss of memory, function, and changes in behavior. Currently, there are 5.8 million Americans diagnosed with AD and this number is on track to increase to 14 million by 2050 (Alzheimer's Association, 2020). With the world's population increasing in overall age, the demand for caregivers will increase as well. Approximately 83% of caregivers in the United States are family members, friends, or other unpaid caregivers (Alzheimer's Association, 2020) who lack the knowledge on the progression of the disease, which leads to increased levels of stress and depression for both the caregiver and the person with AD (Bowen et al., 2014). Normally, caregivers of AD are non-professional practitioners that have not received adequate training, but are tasked with providing intensive at-home, long-term care for patients (Kwon, Ahn, Kim & Park, 2017). With the constant development of this progressive disease, caregivers experience many burdens that lead to considerable emotional, financial, and physical problems.

Roughly 33% of caregivers believe that their mental health has declined due to their caregiving responsibilities (Alzheimer's Impact Movement, 2019). Also, many caregivers state that their desire to participate in leisure activities has declined due to the stresses of caregiving (Hall et al., 2014). While many caregivers feel their role has given them purpose or meaning (51%), these positive emotions often coexist with feelings of

stress or strain (AARP, 2020). Caregivers report physical, emotional, and financial strain, with two in ten reporting they feel alone (AARP, 2020). Non-paid informal caregivers experience increased levels of stress, anxiety, and depression compared to non-caregivers (Garcia-Alberca et al., 2012). These caregivers focus so much on their loved ones that they tend to neglect their own needs. This leads to unhealthy habits like self-isolation, increased agitation, and occupational dissatisfaction (Bowen et al., 2014). Without adequate knowledge or training related to the high demands of caring for a person with AD, caregivers experience negative health consequences such as caregiver burden, depression, or frustration (Leszko, 2019). Over 90% of caregivers feel they have received inadequate guidance for external services from their physicians and are not satisfied with services because of the difficulty in obtaining this information (Bowen et al., 2014). Although there are current resources attempting to decrease the strains of caregiving, caregivers are still experiencing these life-changing burdens (Bowen et al., 2014). It is important to understand that each caregiver has specific needs that need to be addressed to decrease overall burden on caregivers.

Statement of the Problem

There are more than 16 million Americans that provide unpaid care to a person living with AD or other dementias (Alzheimer's Association, 2019). In 2019, Alzheimer's and other dementias cost the nation an estimated \$290 billion dollars and by 2050, these costs are projected to rise as high as \$1.1 trillion (Alzheimer's Disease Facts and Figures, 2020). Without effective interventions, the role of caregivers for those with AD will continue to cause a significant increase in health care costs globally. Caregiver burden is a multidimensional experience that considers an individual's subjective and

objective difficulties (Leszko, 2019). Nearly 60% of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high (Alzheimer's Impact Movement, 2019). Also, one in three dementia caregivers have stated their health has gotten worse due to their care responsibilities (Alzheimer's Impact Movement, 2019). Alzheimer's disease causes devastating effects on caregivers, and when compared with caregivers of people without dementia, over twice as many caregivers for dementia patients indicate substantial emotional, financial, and physical difficulties (Alzheimer's Disease Facts and Figures, 2020). As the aging population continues to increase significantly over the next few decades, the lack of research on how to address the needs of caregivers will impact the public health care system.

According to the American Occupational Therapy Association (AOTA), “Occupational therapy is a skilled health, rehabilitation, and educational service that helps people across the lifespan participate in the things they want and need to do through the therapeutic use of everyday activities (occupations)” (AOTA, 2014). As health care providers, occupational therapists can utilize their expertise in skilled health and education to address the needs of these caregivers. By designing and implementing a community-based participatory needs assessment, we anticipated an “increase in the relevance, acceptability, and usefulness of evidence-based scientific findings in occupational therapy (rehabilitation)” (AOTA & American Occupational Therapy Foundation [AOTF], 2011). Occupational therapy promotes the use of evidence-based practice when delivering interventions because our frame of reference promotes lifelong learning and effective clinical reasoning for occupational therapists. The Master of Science in Occupational Therapy curricular threads have also been integrated into this

research project. The identified curricular threads include psychosocial aspects of care, which focuses on the physical and emotional burden of the caregivers of AD. Therefore, we have developed a cohesive needs assessment based on the current literature of cognitive behavioral therapy and the effectiveness of current needs assessments. It was anticipated that this correlational study of individual caregiver responses would help identify and prioritize the emotional, social, and support needs of caregivers of AD. We anticipated that the data collected will provide future researchers the opportunity to “create novel, theory-based interventions for promoting activity/participation/occupation and improving quality of life” (AOTA & AOTF, 2011).

Occupational therapy interventions target the well-being of an individual by addressing their occupation, their social-emotional needs, and their leisure participation. We examined client factors such as physical and emotional health or performance skills such as social interaction to understand how they influence the client’s daily occupation and coping skills. Also, performance patterns, which include routines and roles, while context and environment, which include educational status, were also addressed (AOTA, 2014). For caregivers, the burden and long-term negative health impacts of caregiving for an individual with AD inhibits their ability to remain healthy and engage in their own meaningful occupations. Occupational therapists can assist in creating balance in their life by teaching the client to manage their roles as a caregiver and as an individual. The multidisciplinary approach involved in caregiving is a health care thread that places significant value in communication between other disciplines as well as collaboration with clients and their caregivers.

Identifying and clarifying the needs of caregivers utilizing a needs assessment has been shown to be an effective method to understand and decrease caregiver burden (Bowen et al., 2014). The purpose of this study was to identify the emotional, social, and support needs of primary caregivers of Alzheimer's patients, analyze their responses on the needs assessment, and recommend resources that could be developed in the future for their specific needs.

Literature Review

We used the following article databases to review the current literature: Proquest Nursing and Allied Health Source, Google Scholar, Pubmed, Cochrane Library, and EBSCO: CINAHL Complete, PsycINFO, Medline, and Academic Search Complete. Search terms included: Alzheimer's disease, caregivers, Cognitive Behavioral Therapy, CBT, dementia, needs assessments, questionnaires, needs, emotional, social, support, interventions and caregiver burden or stress. Any combination of these key search terms was used with the conjunctions "AND" or "OR." Literature searches were conducted between November 2019 to February 2020.

Although the high demands of caregiving cannot be avoided, there are ways to target the needs of caregivers to decrease the overall level of burden that caregivers experience. By utilizing a needs assessment, caregivers can specify their exact needs and identify appropriate resources that may help them with their current life situations. There are many needs assessments that assist caregivers in identifying their needs, but it can be difficult to understand each caregiver's unique needs through a general needs assessment. Each caregiver has different scenarios and situations in which they need assistance, so answering "yes" or "no" questions can make it difficult to express their exact needs.

Eifert & Eddy (2012) stated that one of the distinctive difficulties for caregivers of AD is the progressive nature of the disease. This means that the level of care is always changing, and each caregiver will have their own unique needs at a given point in time. Taking this into consideration, providing multiple and short answer questions will allow for caregivers to specify their own individual needs.

This literature review indicated the need for additional research related to assessing each caregiver's needs. The cognitive behavioral therapy (CBT) frame of reference (FOR) provided essential information that was utilized to develop a specific needs assessment focused on emotional, social, and support needs of the caregivers of AD. The CBT FOR has been recognized as an effective method for caregivers of AD to decrease emotional and behavioral burden. A recent meta-analysis reviewed 12 randomized control trials designed to determine how effective CBT is in decreasing the levels of depression in caregivers of AD. The 12 articles included in this meta-analysis consisted of randomized control designs with outcome evaluations of CBT compared to minimally treated control groups for caregivers. One of the most common conditions addressed in caregivers with the use of CBT was depression, amongst other emotions. The Center of Epidemiologic Studies Depression (CES-D) Scale provides an inventory for depressive symptoms to compare baseline and post-intervention values. Review of these 12 articles showcased that post-intervention CES-D scores decreased significantly for the CBT groups when compared to non-CBT control groups or minimally treated control groups (Kwon et al., 2017). By utilizing a CBT based needs assessment, caregivers can identify their specific emotional, social, and support needs. Analysis of

these responses can support and categorize recommendations for resources to aid them in meeting their needs.

CBT allows caregivers to gain awareness of their emotional status and learn how to cope with their needs properly. Otero, Vasquez, Hermida, Diaz, and Torres (2015) studied the effects of homework assignments as a treatment plan for depression of non-professional caregivers. They studied 89 females with an average age of 56.3; average time of caregiving for 8.6 years and average daily hours dedicated to caregiving was 17.2 hours. The participants in this study represented the average age and daily hours of caregiving for a typical caregiver (Alzheimer's Association, 2019). This study supports the claim that CBT interventions produce decreased levels of depression in female caregivers that have been providing care for many years. It showed that the use of problem-solving assignments in addition to support groups as a supplemental intervention is effective when addressing depression. Typically, CBT revolves around the teaching of coping skills, learning how to modify dysfunctional thoughts, creating social support systems, and participation in pleasant activities (Kwon et al., 2017). With the use of problem-solving skills to understand their current needs, caregivers can reduce their emotional burdens such as depression, anxiety, and stress by becoming aware of their specific needs. The outcomes of homework-based treatment plans to decrease depression in this study facilitated the development of our CBT based needs assessment with short answer questions to aid caregivers in their self-understanding of their current emotional, social, and support needs.

In 2014, Passoni, Moroni, Toraldo, Mazzà, Bertolotti, Vanacore, & Bottini investigated the effectiveness of group CBT by creating three groups treated in different

ways: CBT group intervention, self-help manual, and a control group. Although this study identified decreases in specific feelings such as anxiety, this study also found no decrease in depression amongst all three of the groups. However, this can be attributed to the short-term intervention to combat the increased level of depression that caregivers experience compared to non-caregivers (Passoni et al., 2014). Depression can intrude caregiver emotions with the thought of a progressive and irreversible disease changing their loved one (Passoni et al., 2014). Since this is an inevitable development, some caregivers may have difficulties managing depression. CBT focus groups allowed participants to share and reflect on their feelings, emotions, and behaviors amongst others that are in the same situation as themselves. According to AARP (2020), one in three caregivers are providing care completely alone, with no help from anyone else. In Passoni et al.'s study, when caregivers felt alone, 72% reported experiencing high emotional stress, compared to just 24% of those who do not feel alone (2014). The social aspect of the CBT based needs assessment allows caregivers to understand the importance of social support systems and how it can decrease their emotional stress. With implementation of individual support systems, there may be more effective results in decreasing depression (Passoni et al., 2014). A CBT based needs assessment provides insight on caregiver social and support needs in relation to their current emotional needs.

The aforementioned article found that group CBT decreased levels of anxiety when compared to the self-help manual and control group interventions. This can be attributed to the structure of group therapy which uses participation from caregivers to discuss their cognitive and behavioral experiences and share their care-related problems with other caregivers (Passoni et al., 2014). Group CBT has been shown to work to treat

perceived stress, overall life stress, stress specific to caregiving, and psychological distress. Anxiety and stress can be tested through psychophysiological methods to determine the levels of secreted cortisol levels in the saliva of caregivers (Abouafia-Brakhaa, Suchecki, Gouveia-Paulino, Nitrini, & Ptak, 2013). The comparison between group CBT and psychoeducation group programs revealed that there is an association of a greater decrease in salivary cortisol levels with group CBT than psychoeducation group programs (Abouafia-Brakhaa et al., 2013). This article provided insight on physiological changes and effectiveness of CBT for improving caregiver emotional health. Therefore, we determined that a CBT based needs assessment may provide caregivers with a better understanding of their emotional, social, and support needs to improve their overall health and well-being.

Based on the current literature, statistics on caregiver burden and available resources for these burdens indicate that caregivers who have access to these resources may experience decreased levels of burden. Although this should be a positive outcome, caregivers continue to be negatively impacted by the demands and strains of their role. The recent study on needs assessments of memory disorder patients hypothesized that even with proper intervention implementation, the heavy demands of being a caregiver are still greater than the services provided to them (Bowen et al., 2014). This research created a needs assessment questionnaire that examined their current living situations, safety, physical state, level of independence, activities of daily living (ADLs) and instrumental activities of daily living (IADLs), caregiver education, and available resources and services (Bowen et al., 2014). Overall, this study quantitatively identified the needs of both the patient and the caregiver; they answered it together with a total of

204 questions completed. With this well-structured and extensive needs assessment, Bowen and the other researchers were able to understand and pinpoint caregiver needs by evaluating these areas of caregiving. They concluded that there must be a better understanding of patient and caregiver needs to address caregiver burden. The categorical structure of their study influenced our CBT based needs assessment by categorizing the emotional, social, and support domain layout.

The research findings in a needs assessment of memory disorder patients demonstrated that over 80% of caregivers were not formally trained, they did not receive any external aide, both the patient and caregiver often slept less than six hours a night, and would both benefit from more exercise (Bowen et al., 2014). Additionally, over half of the participants would like to engage in clinical trials to prepare for future endeavors because ADLs and IADLs for patients could be very time consuming for the caregivers at the expense of their own personal, physical, spiritual, emotional, mental, and medical needs (Bowen et al., 2014). Over 90% of caregivers felt they received inadequate guidance for external services from their physician and were not satisfied with services because of the difficulty to obtain this information (Bowen et al., 2014). A research study on emotional exhaustion and its effect on chronic diseases, somatic symptoms, and social dysfunction, included a collection of sociodemographic data and a health indicator questionnaire. The questionnaire consisted of 10 open and closed questions to identify caregivers' marital status, education, children, the number of children they live with, activities they carry out, and their health (Campos-Puente et al., 2019). The researchers wanted to determine if there was a link between caregiver emotional exhaustion and its effects on chronic diseases, somatic symptoms, and social dysfunction. The findings of

this study confirm the direct link between emotional exhaustion with the number of chronic diseases, somatic symptoms, and social dysfunctions. In other words, informal caregivers experience emotional burnout that leads to decreased quality of life through negative health and physical effects of caregiving. To prevent emotional burnout, awareness of emotions while caregiving needs to be brought to the caregivers' attention. Based on this, questions addressing caregiver emotions were implemented into the needs assessment to further understand the emotional needs of caregivers of people with AD to prevent emotional burnout.

In a recent systematic review of quantitative and qualitative studies to understand the needs of caregivers of people with AD, it was established that health care professionals must understand the needs of caregivers in order to reduce caregiver burden (Novais, Dauphinot, Korlak-Salmon, & Mouchoux, 2017). Caregivers' needs change with the progression of the disease, so there needs to be regular assessments of their needs to provide the proper resources to them (Novais et al., 2017). Quantitative instruments develop programs and interventions while qualitative approaches provide an in-depth analysis of their specific needs based on these instruments (Novais et al., 2017). Each patient with AD and their caregiver has unique needs depending on the progression of the disease and caregiver resources; this is why incorporating both qualitative and quantitative data when measuring caregiver needs will provide a better understanding for the health care professional on how to address their individual needs appropriately.

As mentioned earlier, there are many formal resources that provide support and education for caregivers, but caregivers are not utilizing them to their advantage. There is conclusive research on the underutilization of these resources, and there are several

reasons caregivers are disinclined to use them. Many caregivers believe venturing out for assistance is unnecessary due to the normative expectations of their obligation and loyalty to their loved ones (Eifert & Eddy, 2012). Some family members would prefer to keep this information private and keep everything “normal” to prevent any mistreatment or stigma towards their loved one (Eifert & Eddy, 2012). Proper education on the drawbacks to these beliefs should prevent underutilization of resources for caregivers. A CBT based needs assessment should provide insight on unmet needs by allowing caregivers to indicate whether they are lacking emotional, social, and or support during their role as a caregiver. This will allow for integration of appropriate resources that caregivers perceive as necessary to prevent further decline in their health.

After reviewing the current literature related to CBT and needs assessments for caregivers of AD, the development of a needs assessment with CBT based principles was clearly indicated. A CBT based needs assessment provides insight on caregiver maladapted emotions and unmet social and support needs. Reviewing the literature directed proper formatting and structuring of questions to optimize caregiver insight on their exact needs. This needs assessment, with questions based on the CBT FOR, facilitated a direct focus on caregiver emotional, social, and support needs by applying quantitative and qualitative methods to determine future steps in improving these unmet needs of caregivers of AD.

Statement of Purpose

The purpose of this study was to analyze the emotional, social, and support needs involved as a primary caregiver of a patient diagnosed with AD. A needs assessment based on the CBT FOR was designed with the intent of collecting both qualitative and

quantitative data on the specific needs of primary caregivers of patients with AD. This needs assessment was created and sectioned into multiple themes based on previous research, the CBT FOR, the AOTA Research agenda, and the MSOT curricular threads. Of all the themes identified in the research, we focused on emotional, social, and support needs. By creating this correlational study of individual caregiver responses, we predicted that we would be able to identify the critical and specific needs of caregivers of people with AD. The main goal of the study was to identify the caregiver's needs to allow future research to create recommendations based on our findings to reduce the burden experienced by caregivers of people with AD.

Theoretical Framework

CBT is a form of psychological treatment that has shown to be effective for a variety of psychological problems including anxiety, depression, and severe mental illnesses (American Psychological Association [APA], 2017). CBT allows caregivers to recognize and evaluate their distorted thoughts, develop an understanding of their behaviors, and understand their current emotions (APA, 2017). Caregivers can enhance their cognitive and behavioral skills to influence their abilities to cope with the burdens of being a caregiver. By changing current cognitive and behavioral characteristics, caregivers experience decreases in anxiety, depression, and stress levels (Kwon et al., 2017). CBT has been shown to increase the quality of life for caregivers of people with AD by identifying areas in their life that need attention (Aboulafia-Brakha et al., 2014). A systematic review on CBT indicated that the coping strategies and emotional regulation techniques used in CBT have been shown to decrease levels of depression in caregivers of people with AD (Kwon et al., 2017). Through face-to-face, group or individual CBT,

caregivers learn how to incorporate specific management protocols to reduce their emotional burdens. This evidence directly influenced the selection of CBT as a FOR to develop a needs assessment to analyze and identify the importance of emotional, social, and support needs in reducing caregiver burden.

According to the current research, using CBT for caregivers of people with AD is one of the most effective forms of treatment for this population to decrease levels of depression, anxiety, and stress (Kwon et al., 2017; Abouafia-Brakha et al., 2014). When compared to different forms of therapy or interventions, CBT has been shown to be more effective in decreasing emotional, social, and physical caregiver burdens. CBT helps caregivers to understand their current emotions and how these emotions influence their behaviors. CBT aims to change the cycle of dysfunctional thoughts, behaviors, and emotions through the implementation of coping skills for stressful and difficult situations (Kwon et al., 2017). Implementing a needs assessment based on CBT will allow caregivers to understand their current emotional, social and support needs as a caregiver. Analysis of these results will help future researchers and health care workers recommend and or develop proper resources to mitigate progressions of caregiver burdens.

Methodology

Research in Design and Protocol

The needs assessment was designed in both a manual and online format. With the recent COVID-19 pandemic, shifting towards the online version was the safest and most efficient way to collect data. We administered a needs assessment focusing on emotional, social, and support burden experienced by caregivers of people with AD. The assessment starts with a demographic section consisting of nine questions focused on general

demographic information about the caregivers. In this section, caregivers were asked questions about education levels, yearly income, gender, if they are the primary caregiver, if they are related to the patient, how long they have been providing care, whether they were paid or not, and if they receive any outside help while providing care for their patients. We designed 15 questions specific to three areas of caregiver burden. Four questions focused on the caregiver emotional burdens, five questions on social burdens, and the remaining six focused on their support burdens. These questions were randomly distributed throughout the needs assessment. Of the 15 questions, the majority were multiple choice questions consisting of roughly five responses for the caregiver to choose from. There are six questions that include an “other” option where the caregiver can freely respond to the question with their own words instead of picking from the ones provided for them. Participants were given the option to click “Prefer not to answer” if they were uncomfortable with answering a specific question. Also, one “yes or no” question, asked the caregiver if the physician of the patient asked about their needs as a caregiver. Two optional questions were included so that caregivers could respond freely in an open text box.

Originally, a physical copy of the needs assessment was available for caregivers who wanted to fill out the questionnaire manually (see Appendix A), as well as a link to the flyer and online version of the needs assessment for participants who wanted to complete questions online (see Appendix B). As mentioned, due to the pandemic, the online format became the only form of the needs assessment. The needs assessment was obtained and distributed through a link to Survey Monkey, which allowed participants to fill out the needs assessment from the safety of their home. Due to the anonymity of the

needs assessment, we anticipated to receive more honest responses compared to other types of methodology that require participant personal information. Lastly, using this style of data collection allowed for a vast amount of information to be collected on a broad range of topics within a short period.

Recruitment Procedures

We partnered with Alzheimer's Orange County (OC) and data was collected through a variety of outreach methods with their caregiver network. Alzheimer's OC reviewed and verified the needs assessment and outlined their confidentiality needs prior to agreeing to partnering with us on this study. Originally, the primary method of data collection was to take place at the Dementia Family Caregiver Conference hosted by Alzheimer's OC (see Appendix E). The secondary method to collect data was through Alzheimer's OC's email listing to distribute the flyer and the link to the needs assessment on SurveyMonkey to their caregiver network. Participants at the conference would have been verbally informed about their participation rights prior to the 15-questions. (see Appendix D). We would have been present at the conference to answer questions about the needs assessment, help clarify participant rights, and hand out flyers with links to the online version for those conference participants that wanted to complete the assessment at a later time. To obtain as many caregiver responses as possible, we wanted to provide the needs assessment both in-person and with a link to an online version. With the current pandemic, the SurveyMonkey version of the needs assessment became the only form of data collection as it enabled the caregivers from Alzheimer's OC's email list to fill out the need assessment at home. Instructions on how to access the link and fill out the needs assessment were provided to the caregivers just as it would have intended to be at the

conference. All physical documents that would have been given out in-person were provided as a PDF version along with the link.

Data Collection and Analysis

We analyzed 57 completed needs assessments and input the responses onto a data collection form in Microsoft Excel. We compiled, scored, and analyzed the data collected to deduce the emotional, social and support needs from the responses by caregivers within the network and shared the results with the Family Support Specialist at Alzheimer's OC. We analyzed the results from the needs assessments using an Excel Scoring Sheet to indicate the trends found within the responses, as well as to decipher the areas of need as well as what area(s) can be improved for these caregivers (see Appendix C). The needs assessment has a mixed-methods concept, which consists of multiple-choice questions representing quantitative responses and short answer questions consisting of qualitative responses.

All responses received from participants were analyzed to understand the areas of caregiver needs by providing descriptive and statistical analyses on the percentages of how each caregiver responded individually and collectively as a group. We deciphered what type of needs were lacking depending on each answer and the category they belonged to. We then correlated the responses with each demographic question. Each question of the needs assessment was categorized as either emotional, social, or support on the scoring sheet (see Appendix C). From these scores, we tallied which answers were selected the most or the least. We recorded every response and compared them with the demographic information provided by each caregiver. The quantitative responses were analyzed to find any common themes within answers. The results of the qualitative

responses were compared in the same manner as the quantitative results. The qualitative responses emphasized that every individual caregiver may have unique needs that a quantitative method might not address alone. Once all the results were compiled, categorized, and analyzed, we determined common trends based on the responses in order to better understand which areas the caregiver identified that they needed assistance.

Ethical and Legal Considerations

Ethical issues were considered throughout the duration of the project by addressing anonymity, informed consent, storage of data, and benefits of the research for both caregivers and those receiving care. To maintain confidentiality, participants did not provide their names when completing the informed consent form or during the demographic intake information (see Appendix D). The informed consent is accessible on the physical copy and online version of the needs assessment. The informed consent includes a description of what the study entails, the time required by the participant to complete the needs assessment, risks and benefits, information regarding reimbursement, participants' rights, the contact information of the research advisor and additional contact information for the Vice-President of Stanbridge University if participants are concerned. Participants consented by checking an agreement box instead of a traditional signature to maintain anonymity and privacy of personal information.

After all the data was extracted from the online version of the needs assessment, the online responses were encrypted and stored in a Stanbridge University email which was password protected. Only the researchers had access to all the data that was collected during the duration of the study. We collaborated with Alzheimer's OC to develop and gain access to their caregiver network. The organization assisted with the recruitment of

participants and provided input and suggestions on how to introduce this needs assessment to their network in order to secure an optimal amount of responses. With the online nature of this needs assessment, additional privacy measures such as eliminating potential bias or breach in confidentiality were taken.

Results

We analyzed the results of 57 participants who completed the needs assessment, with the demographic portion revealing 73.68% being above the age of 65 and 71.93% being female. 22.81% of caregivers reported having at least a high school diploma with 33.33% having a bachelor's degree and 29.82% having a master's degree. 87.72% of caregivers reported being the primary caretaker, with 47.37% reporting that they have been caregiving for the individual between 1-5 years and 35.09% caring for the individual between 5–10 years. 54 out of 57 participants were related to the individual they were caring for, with a majority being a spouse or parent of the person with AD. 54.39% reported having help taking care of the individual while 45.61% reported being the sole caregiver.

The emotional, social and support sections indicate that 59.65% reported experiencing that he or she receives the support they need as a caregiver while 31.58% reported they feel their needs are not being met, 8.77% preferred not to specify this response. Of the 57 caregivers, only two reported that they receive financial compensation for their caregiving. Caregivers reported similar emotions while caregiving with the top three being stress, anxiety, and depression. On a typical day of caregiving, a majority of individuals reported feeling these emotions 4-6 hours a day at 29.82%, with 1-2 hours and 7-10 hours being reported by 28.97%% of individuals. Support systems of

caregivers included family assistance (28.07%), self-coping strategies (26.32%), and religious and spiritual acts (14.04%), friends or social activities (5.26%), or none (5.26%). When asked how effective their social support was, 38.60% reported effective while 35.09% reported somewhat effective and 10.53% reported neutral. Aspects of life needing more support included emotional (66.07%), physical (17.86%), and financial (5.36%). Caregivers reported needing improvement in the following areas: emotional wellbeing (35.09%), assistance with caregiving (31.58%), and personal or physical health (15.79%). On a typical week of caregiving, 15.79% of individuals reported spending 0-1 hours on social activities, 45.61% reported 1-3 hours, and 12.28% reported 7-10 hours. When asked “Does the patient’s physician or health care provider ask about your needs as a caregiver?” 66.67% responded “No.” When asked to rate the effectiveness of his or her coping strategies as a caregiver, 40.35% responded somewhat effective, 36.84% effective, and 12.28% reported that their coping mechanisms were very effective. When asked in a free response question format, “What could make coping mechanisms more effective?” caregivers commonly responded with skill development/training, access to resources, time away from caregiving, counseling, more free time, and understanding from family and friends. The most important form of support rated by caregivers at 57.89% was time away from caregiving with emotional support following at 35.09%. Support missing from caregivers included time away from caregiving (58.93%), emotional support (23.21%). A majority of caregivers reported receiving support from family and friends (43.86%), in-person support groups (15.79%), and online support groups (14.04%). The biggest barrier to attending social gatherings is COVID-19, with 50% reporting the pandemic as the main barrier. Assistance with caregiving (30.36%)

and time management (8.93%) followed COVID-19 as the largest barriers to attending social gatherings. Social groups that caregivers interacted with the most included family (40.35%), friends (21.05), religious and spiritual groups (14.04%), and social groups (8.77%). The last question of the survey asked about what activities caregivers enjoyed participating in and had the option of choosing more than one response. Caregivers reported enjoying participation in the following activities: physical exercise (57.89%), social activities (49.12%), and leisure activities (38.60%).

Discussion

The purpose of this study was to analyze the emotional, social, and support needs involved with being a primary caregiver of a patient diagnosed with AD. This information was collected through the distribution of a needs assessment questionnaire through our partnership with Alzheimer's OC. Due to complications with COVID-19, and changes in state mandate for public gatherings, we were unable to manually distribute our questionnaire at the originally intended location, the Dementia Family Caregiver Conference. Because the questionnaire was also available in a digital copy and administered through Survey Monkey, a secure online surveying platform, it now became the primary source of data collection.

The results, from the 57 individual caregivers who participated, indicated that a majority of caregivers surveyed were above the age of 65 years old, identified as females, and reported holding an education level above a high school diploma. The data suggests that most caregivers were caring for a relative, unpaid for their services, and were the sole primary caregiver of the individual with most receiving no financial support for their services. Specific trends in the results indicate the commonly experienced emotions by

the caregivers were stress and anxiety, which can largely be attributed to their unmet needs, with particular emphasis on the lack of emotional support needs and respite, meaning time away from caregiving. A majority of the caregivers' responses alluded to not having enough time for themselves because they are solely preoccupied with taking care of the individual diagnosed with AD. With the additional stress of COVID-19 regulations, caregivers are experiencing burden even more than previously due to restrictions on social interactions; with many reporting feelings of isolation while caring for their relatives. It is recommended that caregiver needs are addressed and identified to ultimately reduce the amount of burden that is experienced by implementing appropriate resources and treatment for established needs.

Implications

The Master of Science in Occupational Therapy curricular threads identify the physical and emotional burden of caregivers, a psychosocial aspect of care, which is why we focused on analyzing data about caregiver emotional, social, and support needs. The research outcomes provided direct feedback about the specific social, emotional and support needs that caregivers believe they are lacking and indicates opportunities to address these needs by future occupational therapists such as improving activity and occupational participation (AOTA & AOTF, 2011). These outcomes may benefit occupational therapists by specifically addressing the emotional, social, and support needs of caregivers for patient with AD. The results of this study can lead to further research attempts to address other areas such as aspects of physical and financial needs that also need to be assessed to reduce caregiver burden. Based on the data, the next step of research would be to establish effective resources and treatments for caregivers,

specific to their social, emotional and support needs. With the current 5.8 million Americans living with AD and frequent underutilization of available resources by caregivers, the prevalence of caregiver burden will continue. There is a need for further research in order to implement appropriate resources and treatments for the overwhelming negative impact on caregivers of people with AD.

Limitations

We acknowledge that there are limiting factors that need to be taken into consideration when interpreting the results of this study. Along with the current pandemic that resulted in data collection to an online version only, other possible limitations include a lack of a randomized selection, and questions that address only 3 categories of caregiver burden. All of the data collected was distributed to caregivers in the Alzheimer's OC network, which limited the sample size to caregivers within one network and these caregivers live primarily in the Orange County zip codes. Also, by switching to an online version only, the target population was limited to the specific caregivers that were able to receive the needs assessment link and had the technology resources to complete it. For these reasons, the results from this study may not be generalizable. Future analysis suggests that broadening the recruitment to include random organizations for caregivers of patients with AD in different counties, increasing the amount of questions asked in other categories related to caregiver burden, as well as providing online and in-person options, would provide a broader range of data collection.

Conclusion

While many caregivers rely on health care professionals such as doctors or nurses to provide information on becoming a caregiver, very few report having a conversation

about the role and expectations required. Caregivers of patients with AD who lack the knowledge and skills required of caregivers can lead to many detrimental health deficits that decrease their overall well-being. Although the role of caregiving provides a sense of purpose, these caregivers experience physical, emotional, and social strain that leads to their own health complications. Once designated needs have been established, future studies can research the effectiveness of resources based on our results to efficiently target and improve caregiver burden and overall health. With the current COVID-19 pandemic, patients with AD may forget to abide by precautions, leading caregivers to believe they should isolate themselves even more and lead to further social needs (AARP, 2020). By utilizing the CBT domains of emotional, social and support, this needs assessment can be used as a stepping stone to produce applicable and reliable resources by indicating caregiver specific needs and fully understanding the burdens of caregivers for patients with AD to ultimately prevent further decline in their overall health.

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Appendix A

Caregiver Needs Assessment

Caregiver Needs Assessment

Description: You are invited to participate in a research study about your experience as a caregiver of an individual with Alzheimer’s Disease. You will be asked to complete a short questionnaire where you will answer questions pertaining to your needs as a caregiver. This questionnaire will not ask any identifying information and all results will remain anonymous.

By checking the box “I agree” I have been informed of my participant rights and agree and consent to participate.

Check box: I agree I disagree Date: _____

Demographic Information			
Age:	Gender: A. Male B. Female C. Other: _____ D. Prefer not to say		
Highest education level: A. Some high school B. High school Diploma C. Trade School D. Bachelor’s Degree E. Master’s Degree F. Doctorate Degree	<table border="1" style="width: 100%;"> <tr> <td style="width: 50%; vertical-align: top;"> Are you the primary caregiver for this individual? A. Yes B. No </td> <td style="width: 50%; vertical-align: top;"> Are you related to the individual? A. Yes, I am their _____ B. No </td> </tr> </table>	Are you the primary caregiver for this individual? A. Yes B. No	Are you related to the individual? A. Yes, I am their _____ B. No
Are you the primary caregiver for this individual? A. Yes B. No	Are you related to the individual? A. Yes, I am their _____ B. No		
Total Yearly Income: A. Less than 50,000 B. 51,000-100,000 C. 101,000-150,000 D. >150,000 E. Prefer not to answer	<table border="1" style="width: 100%;"> <tr> <td style="width: 100%;"> Does anyone else help you care for this individual? A. Yes B. No </td> </tr> <tr> <td style="width: 100%;"> Do you feel you have the support you need as a caregiver? A. Yes B. No </td> </tr> </table>	Does anyone else help you care for this individual? A. Yes B. No	Do you feel you have the support you need as a caregiver? A. Yes B. No
Does anyone else help you care for this individual? A. Yes B. No			
Do you feel you have the support you need as a caregiver? A. Yes B. No			
How long have you been caring for this individual? A. 6 months-1 year B. 1-5 years C. 5-10 years D. 10+ years	Are you a paid caregiver? A. Yes B. No C. I would prefer not to answer		

<p>Caregiver Needs Assessment: Circle the answer in each question that best describes your caregiver experience</p>		
<p>Which emotion do most often experience as a caregiver?</p> <ul style="list-style-type: none"> a. Personally satisfied b. Proud c. Stressed d. Depressed e. Anxious <p>Other:</p> <p>_____</p> <p>_____</p>	<p>On a typical day of caregiving, how many hours would you say you feel these emotions?</p> <ul style="list-style-type: none"> a. 0-1 hours b. 1-2 hours c. 2-4 hours d. 4-6 hours e. 7-10 hours 	<p>Which best reflects your support system?</p> <ul style="list-style-type: none"> a. Family assistance b. Friends or social activities c. Religious/Spiritual acts d. Clubs or Memberships e. Self coping strategies f. None <p>Other:</p> <p>_____</p> <p>_____</p>
<p>How effective is your social system?</p> <ul style="list-style-type: none"> a. Very effective b. Effective c. Neutral d. Somewhat effective e. Not at all effective 	<p>Which aspect of your life do you feel needs more support?</p> <ul style="list-style-type: none"> a. Emotional b. Financial c. Legal d. Medical e. Housing f. Physical 	<p>Is there anything specific in your life that you wish could improve?</p> <ul style="list-style-type: none"> a. Time management b. Finances or income c. Assistance with caregiving d. Resources for caregiving e. Personal (Physical) health f. Emotional well-being
<p>On a typical day of caregiving, how many hours do you spend per week engaging in social activities?</p> <ul style="list-style-type: none"> a. 0-1 hour b. 1-3 hours c. 4-6 hours d. 7-10 hours e. 10+ hours f. None 	<p>Does the patient's physician or health care provider ask about your needs as a caregiver?</p> <ul style="list-style-type: none"> a. Yes b. No 	<p>How effective do you feel your coping strategies are:</p> <ul style="list-style-type: none"> a. Very Effective b. Effective c. Neutral d. Somewhat effective e. Not effective
<p style="text-align: center;">Is there anything that could make your coping strategies more effective: (optional)</p> <div style="border: 1px solid black; height: 100px; width: 100%;"></div>		

Appendix B

Flyer for Online Caregiver Needs Assessment

Caregiver Needs Assessment

Website: www.Surveymonkey.com/efji38379r

Steps:

1. Type in the website URL given above into your internet browser.
2. Complete the informed consent form, demographic form, and survey questions.
3. When all questions are completed, click the green "DONE" button on the bottom of the survey.
4. This concludes the survey, on behalf of our thesis group we thank you for participating in our study.

If you have any questions please feel free to email us at
Caregiverneeds@stanbride.edu



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Appendix C

Caregiver Needs Assessment Scoring Sheet

Demographics:							
Age:							
Gender:	A)	B)	C)	D)			
Highest education level:	A)	B)	C)	D)	E)	F)	
Are you the primary caregiver for this indi	A)	B)					
Are you related to the individual?	A)	B)					
How long have you been caring for this inc	A)	B)	C)	D)	E)		
Does anyone else help you care for this ind	A)	B)					
Are you a paid caregiver?	A)	B)	C)				
Do you feel you have the support you need	A)	B)					
Emotional:							
Which emotion do most often experience a	A)	B)	C)	D)	E)	Other:	
On a typical day of caregiving, how many	A)	B)	C)	D)	E)		
How effective do you feel your coping stra	A)	B)	C)	D)	E)		
Is there anything that could make your cop	Free RA)	EnB) Sup	C) Social []				
Support:							
Which best reflects your support system?	A)	B)	C)	D)	E)	F)	Other:
Which aspect of your life do you feel need:	A)	B)	C)	D)	E)	F)	
Is there anything specific in your life that y	A)	B)	C)	D)	E)		
Does the patient's physician or health care	A)	B)					
What type of support do you feel is the mo	A)	B)	C)	D)	E)		Other:
What type of support do you feel is missin	A)	B)	C)	D)	E)		Other:
How do you receive support?	A)	B)	C)	D)	E)	F)	Other:
Social:							
On a typical day of caregiving, how many	A)	B)	C)	D)	E)		
Are there any barriers to attending social g	A)	B)	C)	D)	E)		
Which social group do you interact with th	A)	B)	C)	D)	E)	F)	
What types of activities do you like to part	A)	B)	C)	D)	E)	F)	Other:
How effective is your social system?	A)	B)	C)	D)	E)		

Appendix D

Consent Form

STANBRIDGE UNIVERSITY RESEARCH CONSENT FORM

Description: You are invited to participate in a research study about your experience as a caregiver of an individual with Alzheimer's Disease. You will be asked to complete a short questionnaire where you will answer questions pertaining to your needs as a caregiver. This questionnaire will not ask any identifying information and all results will remain anonymous.

Intent: The purpose of this study is to identify needs of caregivers, caring for individuals with Alzheimer's Disease. Through this questionnaire, we will identify needs that are currently being met and what needs are not being met in order to better assist caregivers.

Your Time Involvement: Your participation will take approximately five to ten minutes to complete the questionnaire.

Risks and Benefits: While there may not be any direct benefits for you through completion of this survey, the results of the survey can provide greater knowledge for medical personnel about what caregivers still need to provide care to the best of their ability. There are no known risks with participating in this study. As always, there may be a chance of identification; however, in order to decrease this risk questions will remain anonymous.

Payment: There will be no payment for participation in this study.

Participant Rights: If you have read and signed this form you are consenting to participate in this study. Participation in this study is voluntary and you have the right to withdraw at any point without penalty. Your alternative is to not participate in this study. You have the right to refuse to answer specific questions. Your identity will not be disclosed at any time. The results of this study may be disseminated at professional meetings, shared with other medical professionals, or published in scientific journals. By checking the box "I agree", I have been informed of my participant rights and agree and consent to participate.

Contact Information: If you have any questions about this research you may contact the Faculty Advisor: Denise Miller by email at dmiller@stanbridge.edu

Check box: I agree I disagree Date: _____

Appendix E

Research Site Agreement Form

Research Site Agreement Form
Master of Science in Occupational Therapy

AGREEMENT

Research Site: Alzheimer's Orange County

Research Site Address: 2515 McCabe Way #200 Irvine, CA 92614

Title of Proposed Research: Understanding the Social, Support and Emotional Needs of Caregivers of patients with Alzheimer's

STANBRIDGE UNIVERSITY MASTER OF SCIENCE IN OCCUPATIONAL THERAPY DEGREE PROGRAM

Student Investigator(s) Name(s):

1. Xylie Parker
2. Anthony Valencia
3. Alexander Mauter
4. Natasha Florez

Principle Student Investigator Name: Anthony Valencia

Email address: anthonyvalencia9995@gmail.com Phone Number: (626) 863-4725

Duration of the study: April 2020- November 2020

Authorization Effective Date: April 1, 2020 Authorization Expiration Date: November 2, 2020

Allowed Number of Contact Hours: _____ The study will be completed by (date): November 20, 2020

Description of Research:

Our research objective is to study the social, support and emotional needs of Caregiver's of Alzheimer's

patients by administering a needs assessment and analyzing their responses. Research analysis about

the needs and experiences as a caregiver will help provide recommendations and/or develop resources

to support their needs and improve the quality of their life and role as caregiver.



IRB Application Number	MSOT09-014
Date	04/26/2020
Level of Review	Exempt
Application Approved	X
Conditional Approval	
Disapproved	
Comments	
Signature of IRB Chair	