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How do informal caregivers of a person with dementia experience stress and which supports help mitigate the effect of these stressors?

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How do informal caregivers of a person with dementia experience stress and which supports help mitigate the effect of these stressors?

Presented in Partial Fulfillment of the
Requirements for the Degree of
Doctor of Occupational Therapy

Eastern Kentucky University
College of Health Sciences
Department of Occupational Science and Occupational Therapy

Kwandra Brinson

2023

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Executive Summary

Background:

Alzheimer's disease or related dementias (ADRD) are one of the most rapidly growing epidemics that the world is facing. Caring for a person with ADRD is challenging and often causes informal caregivers stress, loneliness, and social isolation.

Purpose:

The aim of this qualitative instrumental case study was to obtain a better understanding of how informal caregivers of persons with ADRD experience stress and which supports helped mitigate the effect of these stressors in their role as a caregiver.

Theoretical Framework.

The Model of Human Occupation focuses on therapy helping persons to engage in occupational behaviors that maintain, restore, reorganize, or develop their capacity, motive, or lifestyle.

Methods.

Semi-structured interview was used as the data collection tool to gain knowledge from the caregiver on how they experienced stress and what supports help to mitigate the effect of these stressors, as this was an effective way to gain the thoughts and concerns from this population.

Results.

There were three participants that were interviewed for the study. Fourteen categories were identified by grouping the codes together and three themes developed from those categories. The three themes were Bad days are rough, little damper on everybody, and we try to keep normal.

Conclusions:

The participants' stressors were consistent with other studies that stated behaviors cause increased burden on caregivers. Although there are programs and assistance for caregivers, there is a deficit in caregivers' referrals to resources and occupational therapy.

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EASTERN KENTUCKY UNIVERSITY

COLLEGE OF HEALTH SCIENCES

DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL THERAPY

CERTIFICATION OF AUTHORSHIP

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Certification of Authorship: I hereby certify that I am the author of this document and that any assistance I received in its preparation is fully acknowledged and disclosed in the document. I have also cited all sources from which I obtained data, ideas, or words that are copied directly or paraphrased in the document. Sources are properly credited according to accepted standards for professional publications. I also certify that this paper was prepared by me for this purpose.

Student's Signature: Kwandra Brinson

Date of Submission: 5/5/2023

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Section 1: Nature of the Project and Problem Identification

Introduction

Globally, in 2015 informal caregivers provided an estimated 82 million hours of care in the home for people living with dementia (Engel et al., 2022). Alzheimer's disease or related dementias (ADRD) are one of the most rapidly growing epidemics that the world is facing. According to Alzheimer's Association (2020), there were an estimated 3.5 million Americans living with dementia in 2020 and this number is expected to increase to 13.5 million by 2050. As the life span increases, ADRDs are becoming more prominent in people aged sixty-five and older (Ahn et al., 2019; Vann, 2016). Many people with dementia have a desire to age in place (AIP). Aging in place is commonly defined as the "ability to live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level" (Ahn et al., 2019). Most often people with ADRD who are maintaining their AIP status receive support from family and friends who provide unpaid care and support (Engel et al., 2022). These caregivers are sometimes referred to as "invisible second patients" as they often experience increased rates of depression, anxiety, stress, and physical illnesses (Engel et al., 2022). Caring for a person with ADRD is challenging and often causes these informal caregivers to give up social activities which results in loneliness, social isolation and decreased quality of life (Engel et al., 2022). Helping informal caregivers to manage stress and create balance in their routine may improve their quality of life.

Caregivers are essential in supporting individuals with ADRD with AIP (Wawrziczny et al., 2020). There are many behavioral and environmental challenges to consider for people living with dementia. These challenges impact caregivers, as well as their ability to live safely and alone in their home. Caregivers' quality of life is impacted due to the change in roles, tasks, and

responsibilities (Wawrziczny et al., 2020). The change in roles causes stress and places burdens on caregivers. This study will explore how informal caregivers of people with ADRD cope with the stressors to have a less stressful experience and will explore how occupational therapy (OT) can best support the caregivers to experience greater quality of life.

One outcome of OT services is to improve quality of life for persons, groups and populations (American Occupational Therapy Association [AOTA], 2020). Caregivers of people with ADRD is one population that is currently underserved. Occupational therapy interventions for persons with ADRD consist of caregiver education, cognitive abilities, environmental adaptations, and safety to improve functional abilities of the person with ADRD (Dooley & Hinojosa, 2004; Piersol et al., 2017; Thinnes & Padilla, 2011). Although OT focuses on improving functional abilities with the person with ADRD, behaviors are usually the barrier to performing their activities of daily living (ADLs) and increases the burden on caregivers (Connors et al., 2020). There have been studies that have shown that OT interventions that are based on sensory stimulations improve behavioral symptoms that impact quality of life, behavioral and emotional problems of the person with ADRD and caregivers (Ávila et al., 2018). OT has the skills available to assist caregivers of persons with ADRD, yet this relationship remains underexplored. Furthermore, despite the fact that OT is shown to impact and improve the persons with ADRD and the caregiver's quality of life, the families affected by ADRD remain with little to no access to these supports that OT can provide. The growing epidemic of people with ADRD will continue to impact informal caregivers, and there is a greater number of persons expected to experience occupational imbalance as a result of taking care of their loved ones with ADRD (Edwards, 2015). Occupational imbalance is described as not having balance between physical, emotional, and social occupations (Edwards, 2015). There is a need for

improved education for caregivers on the disease process, prevention of challenging behaviors and signs and symptoms of fatigue and burnout to better support informal caregivers to improve their quality of life (Edwards, 2015). Although there is evidence that OT can make a significant impact supporting people with ADRD and their caregivers these individuals are rarely referred to occupational therapy (Edward, 2015; Graff et al., 2006). Persons with ADRD and their caregiver often have limited access to education, training and other supports that would help them AIP with greater ease. This study will examine the caregivers stress and how they cope with these stressors. This study will provide insight for OT practitioners to better advocate and support these individuals in their desire to AIP.

Problem Statement

In 2020 informal caregivers provided 15.3 billion hours of unpaid care in the United States (Alzheimer's Disease Facts and Figures, 2021). The unpaid care is estimated at a cost of \$256 billion (about \$790 per person). With this substantial amount of unpaid care, it is evident how many families are affected by caregiving duties, with caregivers experiencing decreased quality of life, increased stressed and burdens associated with the change in roles and duties (Avila et al., 2018). It is important that the care recipients and the caregivers receive effective strategies and interventions to help mitigate these stressors (Raj et al., 2021). Because of the increased demand and strain on the caregivers, there is an increased risk of institutionalization for care recipients (Raj et al., 2021). Effective interventions should help caregivers manage these stressors to help them improve their quality of life but to also help reduce the risk of institutionalization for their care recipient.

Purpose of the Project

This qualitative instrumental case study was conducted to understand how informal caregivers experience stress and manage it in their role.

Project Objective/ Research Question

The aim of this qualitative instrumental case study was to obtain a better understanding of how informal caregivers of persons with ADRD experience stress and which supports helped mitigate the effect of these stressors in their role as a caregiver.

Theoretical Framework

The Model of Human Occupation (MOHO) guided the research in this capstone project. MOHO focuses on therapy helping persons to engage in occupational behaviors that maintain, restore, reorganize, or develop their capacity, motive, or lifestyle (Cole & Tufano, 2020). “Through participation in therapeutic occupations, persons transform themselves into more adaptive and healthier beings” (Kielhofner & Barrett, 1997). MOHO believes that all environmental contexts are influential on a person's internal state of being and overall occupational participation (Cole & Tufano, 2020).

MOHO has three subsystems to help conceptualize the internal variables of a person to assist practitioners in theory to understand things that are otherwise unseen (Cole & Tufano, 2020). The three subsystems are volition, habituation, and performance capacity. Volition is what motivates a person for occupation (Cole & Tufano, 2020). Habituation refers to how a person's occupation fits into their habits or routine (Cole & Tufano, 2020). Performance capacity is when the physical and mental abilities are assessed within the actions and occupational performances (Cole & Tufano, 2020). This study will explore the informal caregiver's volition, habituations, and performance capacity and how they approach and manage their stress.

Significance of the Study

The significance of this study is to better understand the needs of caregivers to support them and the care recipient. One of the goals of *Healthy People 2030* (n.d) is to improve the health and well-being for caregivers and their care recipients. One method to support the caregivers is to ensure they have the resources they need for their health and well-being (Healthy People 2030, n.d.). Occupational therapy has been shown to have a profound impact in supporting individuals with ADRD and their caregivers to promote a better quality of life. Therefore, this study will give more insight into the stressors of caregivers of people with ADRD for OT to better support them to AIP.

Summary

With the increase in people with ADRD in the world, there will be more informal caregivers needing support. Informal caregivers' experiences are important to understand to be able to better support them and their care recipient to ensure a better quality of life. There are many factors that determine how caregivers' approach, manage, and cope with their caregiving tasks. Using a qualitative instrumental case study will allow the caregiver to provide insight on their approach, coping strategies, supports needed and professional approaches that can support and guide them for a better quality of life. This capstone project explored the perceived stressors of informal caregiving for persons with ADRD and coping strategies utilized to manage these stressors in order to gain insights to ways in which occupational therapy can better support these individuals.

Section 2: Review of the Literature

This literature review was developed by searching databases to further understand the research that has been explored on people with ADRD caregivers' stress and how they cope with the stressors. The literature review is organized by first exploring the impact of care on informal caregivers, then the factors that increase caregiver burdens, next caregiver coping strategies, followed by the support for caregivers and concludes with occupational therapy services for people with ADRD and their caregivers.

Impact of Care on Informal Caregivers

There is an estimated 70% of families and close friends that assist people with dementia in their homes (Edwards, 2015). These unpaid individuals are called informal caregivers. In the United States, there are seven million caregivers; this number is estimated to increase to forty million by the year 2050. It is further estimated that in 2050 there will be twenty-eight million disabled and elderly people needing care and many of them with Alzheimer's disease and other dementias (Taylor et al., 2008). Caregiving is associated with negative physical and emotional outcomes in which the caregiver is less likely to engage in preventive health measures and has a greater mortality rate (Contreras et al., 2022). This is a problem for caregivers noted by Healthy People 2030's (n.d.) goal to increase resources and support to improve people with ADRD and their caregiver's health and well-being. There is a strain on the caregiver to provide 24/7 supervision or care which limits social activities and can result in social isolation (Contreras et al., 2022). Forty to 75% of dementia care costs are from informal caregiver's care which exceeds the total medical and formal caregivers' cost (Angeles et al., 2021).

Informal caregivers are usually a spouse, child, family member, friend, or neighbor. There are more female caregivers than male caregivers. Women are disproportionately affected

by this phenomena with women accounting for 65% of informal caregivers in the home, 78% consisting of wives and daughters (Pöysti et al., 2012). Studies have shown that female caregivers have more increased burden than males, with female caregivers experiencing greater stress than men (Baker & Robertson, 2008).

There are various reasons why individuals become caregivers for people with ADRD. Some people provide care out of love, reciprocity, duty, obligation and to prevent admission into an institution (Greenwood & Smith, 2019). Providing care for loved ones with ADRD can be rewarding and stressful at the same time. Making the decision to become a long-term caregiver comes with its own set of challenges. Therefore, it is important to explore the stressors and the educational needs of informal caregivers to help decrease stress and improve their quality of life.

Caregivers are sometimes referred to as “invisible second patients” because of their increased rates of depression, anxiety, stress, and physical illnesses (Engel et al., 2022). Their situation changes the roles, tasks, and responsibilities that affect their quality of life (Wawrziczny et al., 2020). The change of roles causes stress on the caregiver’s physical and mental health, and it affects them financially. Collins and Kishita (2020) reported that caregivers spend more hours per week on care tasks, helping with more activities of daily living, employment complications, and using their own money on care expenses which results in less time for leisure and social activities. These challenges lead to increased stress related disorders and increased rates of depression which affects how caregivers are able to provide care; resulting in decreased quality of life of both caregivers and care recipients (Shoukr et al., 2022). Caregivers not only have more stress-related disorders but also have more physical symptoms, resulting in increased medication, increased rates of hospitalizations, and a greater mortality rate (Oken et al., 2011). Caregivers’ stress is often related to the care recipients' behaviors, cognitive

impairments as well as their dependence on ADL and IADL. Caregivers require assistance to cope and manage their lives as well as that of the care recipient to improve their quality of life.

Factors that Increase Caregiver Burden

There are many aspects that may contribute to the difficulty of caregiving for people with ADRD. Cognitive impairments, behaviors, and decreased ability to perform ADLs and instrumental activities of daily living (IADLs) are the common predictors of caregiver burdens, but it is important to investigate specific burdens that caregivers report that increases their level of stress (Connors et al., 2020). Neuropsychiatric symptoms are reported to cause a considerable amount of burden (Connors et al., 2020). Neuropsychiatric symptoms include behaviors such as delusions, hallucinations, agitation/ aggression, depressions, anxiety, apathy, and sleep disorders (Phan et al., 2019). These findings are consistent with other studies that reported that neuropsychiatric symptoms and decline in ADL and IADL were associated with greater caregiver burden (Cheng, 2017; Connors et al., 2020; Feast et al., 2016; Schoenmakers et al., 2010; van der Lee et al., 2014). Two of the symptoms that people with ADRD experience is agitation and depression and are said to be the most troublesome to caregivers as these behaviors are unpredictable causing an increased burden to the care provided (Connors et al., 2020; Feast et al., 2016). Furthermore, behaviors in people with dementia are noted to be challenging no matter what stage of the disease as safety concerns become more prominent, a contributing factor to the increased burden of care (Allen et al., 2020).

Caregiver Coping Strategies

The caregivers may use coping strategies to decrease stress within the environment. Coping strategies are how people manage stress (Lloyd et al., 2019). Coping strategies are personal and can be reflective of the caregiver's characteristic and relationship with their care

recipients. There are many coping strategies which can have a negative or positive impact on the caregiver and the care recipient. Emotion-focused strategies are the processes in which the person attempts to manage the stressor through acceptance, positive restricting, and humor (Lloyd et al., 2019). Problem-focused strategies attempt to change the situation for the better by alternative solutions, planning task actions to solve or circumvent stressors (Lloyd et al., 2019). Another classification of coping strategies are engagement and disengagement. Engagement strategies are the attempt to actively change the situation through problem solving, or expressed emotions (Balbim et al., 2019). Disengagement strategies refer to the person withdrawing from situations such as avoidance or self-criticism (Balbim et al., 2019). These four coping mechanisms have been labeled and classified, but studies have shown that caregivers coping strategies are influenced by their culture, race, and ethnicity (Balbim et al., 2019).

Coping strategies used by caregivers impact the level and effects of their stress. Lloyd et al. (2019) studied self-compassion and the use of coping strategies and noted that emotional focused strategies were used more in caregivers with higher self-compassion. Although emotional focused strategies were used more in self-compassionate caregivers, it did not relate to caregiver burdens (Lloyd et al., 2019). This can be an indicator that the use of positive coping strategies does not lessen caregiver burdens. A study on stress buffers effecting coping strategies with working informal caregivers reported that emotional focused coping was more directly related to decrease in stress rather than problem focused coping strategies (Morimoto et al., 2019). It suggested that more training of mindfulness could improve caregivers' mental health (Morimoto et al., 2019).

Support for Caregivers

Informal caregivers need support, but the support needed varies from person to person. Informal caregivers are faced with the need for physical, emotional, social, financial, and educational support. Supportive interventions can help improve the quality of life of the care recipient and caregiver and delay institutionalization (Vandepitte et al., 2016). Caregivers have reported that support from family and friends makes a difference, but they are hesitant and feel guilty when reaching out for help which causes more challenges (Contreras et al., 2022). Family and friends' support may help with relieving the burden of care, but some do not have that option. There are several different options of supportive interventions that can help caregivers other than family and friends. Occupational therapy, psychoeducational therapy and behavioral therapy are reported to be supportive intervention to prevent caregivers' burdens but it's important to investigate supportive interventions to relieve stress and duties for the caregivers (Vandepitte et al., 2016). Respite care is a type of formal supportive care that helps relieve or give informal caregivers a break (Brandão et al., 2016; Vandepitte et al., 2016). The goal of respite care is for the informal caregiver to receive temporary rest and relief, take care of their mental and physical health and opportunities to participate in social activities (Wylie et al., 2021). Respite care can be in-home or outside of the home.

Adult Day Services

One type of outside respite care is adult day care services. Adult day services (ADS) allow the care recipient an opportunity to be outside the home to receive and relieve primary care from informal caregivers. Adult day services are reported to have positive benefits to the care recipient and caregiver (Vandepitte et al., 2016). The benefits to the care recipients are decreased behaviors improved sleep quality whereas the caregiver experiences reduce burdens and related

stress factors (Vandepitte et al., 2016). However, a study by Wylie et al. (2020) examined ADS subjectively and objectively from the caregiver and reported that subjectively caregiver ADS improved positive mood but did not decrease negative effects but objectively it acts as a positive emotion and less as a buffer of negative emotions.

Residential Respite Care

Residential respite care are usually for short stay over several days for vacations, special holidays, or to relieve extreme caregiver burdens (Brandão et al., 2016). There were two articles that were identified that explored the utilization of residential respite care and both were international articles and reported lack of knowledge and underuse of the services (Brandão et al., 2016; Sultana & Agius, 2019). An Australian article reported that using residential respite care can increase people staying at home longer (Harrison et al., 2020). Medicare pays for residential respite care, but the recipient must receive hospice services (Medicare.org, n.d.).

In-home Respite Care

In-home respite care allows the care recipient to stay home while the caregivers take time to perform other tasks. Some studies report that in-home is the preferred option for caregivers to mostly attend to home or health task but rarely use for social activities (Vandepitte et al., 2016). Not only that, in home respite is preferred and is also reported to be received positively and with high satisfactions (Vandepitte et al., 2016).

Occupational Therapy Services for People with ADRD and their Caregivers

Occupational therapy at its core is a profession that seeks to achieve health and well-being through “participating in life through engagement in occupation” (AOTA, 2020). The caregiver’s occupation has been altered by their new role, and it impacts the way they engage in occupation. It is important that occupational therapists understand and acknowledge the

caregiver's internal and external factors that impact their well-being in order to help support and educate (Edwards, 2015). Informal caregivers sometime lack formal training and are unaware of environmental adaptations and caregiving strategies (Dooley & Hinojosa, 2004; Piersol et al., 2017; Thinnes & Padilla, 2011).

Informal caregivers may benefit from a partnership with home-based occupational therapy to maintain a care recipient's occupational performance and the health and well-being of the caregivers (Raj et al., 2021). Occupational therapy assessments and interventions determine useable skills and supports to maximize the care recipient's independence in ADL which should increase the quality of life for care recipients (Dooley & Hinojosa, 2004; Piersol et al., 2017; Thinnes & Padilla, 2011). There is moderate strength evidence to support the effectiveness of home-based OT in increasing ADL performance and decreasing the caregiver burdens (Raj et al., 2021). It is important that OT interventions are client-centered and multifaceted to promote performance of daily occupation and improve caregiving tasks for caregivers (Raj et al., 2021). Home-based OT can support the care recipient and the caregiver to facilitate a partnership and custom intervention to their specific needs (Raj et al., 2021).

Occupational therapy's focus when working with people with ADRD and their caregivers are environmental modifications, behavioral reduction, stress management and being a source of community referrals to maximize the care recipient's independence while decreasing caregiver burdens. Client centered approaches allow the OT to focus on the specific task of the individuals. Raji et al. (2021) performed a systematic review that examined home-based OT concerning caregivers' burdens focused on educational interventions to address compensatory strategies, caregivers' skills, and community resources. Within this systematic review the caregivers' burdens were classified as subjective and or objective. The subjective was based on

the emotional response to caregivers' demands and objective referred to the number of hours spent assisting with ADLs. There were nine studies that reported a reduction in caregivers' burden by educating them about dementia-related problems, environmental factors, home modifications, daily routines, and community resources (Raj et al., 2021). Occupational therapy interventions can reduce caregivers' burdens through education, but caregivers are not being educated or referred to OT to gain its benefits. Studies show that caregivers are not being referred and are unaware of the benefits of occupational therapy (Edwards, 2015; Graff et al., 2006).

Summary

Section three explains the methods of this study. The section includes project designs, setting, inclusion/exclusion for participants, project methods, data analysis, ethical concerns, and a timeline of project procedures.

Section 3: Methods

Project Design

This capstone project is a qualitative instrumental case study on how informal caregivers of a person with ADRD experience stress and which supports help mitigate the effect of these stressors in their role as a caregiver. An instrumental case study provides insight into the issues, redraws generalizations or builds theories (Mills et al., n.d.). Semi-structured interviews were conducted with informal caregivers to allow the interviewer to structure questions and probe for more in-depth and trustworthy information (Taylor, 2017).

Setting

Interviews were conducted in a private setting. One of the interviews was in-person at the individual's home and the other two interviews were over the phone.

Inclusion and Exclusion Criteria

Participants of this study were informal caregivers of individuals with ADRDs. The participants were 18 years or older. The care recipients were at different stages of dementia. The care recipients could live in the community and could live separately from the caregiver. The participants were English speaking. This study excluded caregivers who provided care for care recipients in institutions or without a diagnosis of dementia, were non-English speakers, or were formal caregivers.

Recruitment Procedures

This study used purposive sampling. Purposive sampling is identifying a select participant that fits a predetermined criterion (Taylor, 2017). The principal investigator used word of mouth to search for participants through co-workers, family members, friends as well as house of worship members to recruit using verbal script. The verbal recruitment script included

the title, criteria, and contact information for the principal investigator. Once a participant was identified, the researcher reached out by telephone to further explain the study and ensured that participants met the criteria and received verbal consent. The goal was to interview at least one caregiver on their experience as a caregiver of a person with ADRD, with a maximum of five interviewed.

Project Methods

A semi-structured interview ranged from thirty minutes to an hour. Semi-structured interview was used data collection tool to gain knowledge from the caregiver on how they experienced stress and what supports help to mitigate the effect of these stressors in their role as a caregiver, as this was an effective way to gain the thoughts and concerns from this population. The interview was recorded digitally on the researcher's personal password-protected smartphone using the transcription app Otter or on a personal password-protected computer for a virtual interview. The interview consisted of six guiding questions with related probes: 1.) Describe your caregiving situation 2.) What are the changes you have experienced during your time as a caregiver? 3.) What are the stressors that you face as a caregiver? 4.) How do you cope with those stressors? 5.) What are the strategies used to manage your role as a caregiver? 6.) What type of therapy or services have you all received?

Data Analysis

The PI reviewed recorded interviews for each participant multiple times from Otter app and virtual recording before correcting transcribed interviews. The transcriptions were corrected on password-protective computer. Opening coding was then conducted for each interview using in-vivo coding. In-vivo coding uses the exact words or phrases used by participants (Creswell & Poth, 2018). These words and phrases were highlighted and placed in an Excel spreadsheet based

on significance to interview questions and caregiver stressors or core phenomenon. Once codes were placed on spreadsheet the codes were grouped into categories. Categories helped to focus the themes

(Creswell & Poth, 2018). These categories were then reduced to three themes using the common ideas and situations stated by the participants.

Ethical Considerations

Ethical concerns pose issues in research. When performing research, there should be strategic plans to decrease ethical concerns. Researching the problems and concerns of people with dementia and their caregivers can be a sensitive subject and could cause some anxiety. Prior to beginning a study, the professional association code of conduct was reviewed and examined thoroughly for dilemmas and solutions (Creswell & Poth, 2018). This instrumental case study referenced the core values of AOTA. There are seven core values identified which are altruism, equality, freedom, justice, dignity, truth, and prudence (AOTA, 2015). Considering these core values throughout the process of the research was important. Combining the research of Creswell and Creswell (2018) and the AOTA occupational therapy code of ethics core values helped to bridge the ethical issues. Institutional Review Board (IRB) approval ensured the welfare (altruism) of this population was considered (Creswell & Creswell, 2018). The participants were educated they had a right to refuse consent. They had the freedom to choose if they wanted to participate without pressure. There was no deception while collecting data. Information was conveyed to participants in the simplest form orally, written, and electronically (truth). The principal investigator used sound judgment to convey the findings (prudence).

Trustworthiness was established to validate the data. Reflective writing was performed after interviews and during transcription to convey researchers' thoughts, and interpretation of

the data. Reflexivity is the consciousness of the writer to identify their biases, values, and experiences (Creswell & Poth,2018). Defining codes and debriefing data and research process with committee mentor helped the validity and reliability of the data. The PI sought external check by someone that was familiar with the research explored (Creswell & Poth,2018).

Timeline of Project Procedures

- The principal investigator received IRB approval on January 17, 2022 (see Appendix A).
- The principal investigator used word of mouth with verbal recruitment script to attract participants.
- Participants were identified, the principal investigator then contacted the participant to ensure inclusion and obtain a verbal consent.
- The principal investigator performed the interview depending on the participant's preference.
- Review of the data by transcribing the interviews by the Otter app; through active reading the principal investigator developed codes and themes.
- Data finding analyzed by the principal investigator, committee chair and committee member.

Section Four: Results and Discussion

Participant Characteristics

Three participants fit the inclusion criteria and agreed to participate in the study. The participants were given pseudonyms (Janie, Charles, Rosa) to protect their anonymity.

Participants included a niece (Janie), who was a secondary informal caregiver, a husband (Charles), who was a primary caregiver, and a wife (Rosa), who was a primary caregiver.

Table 1. Participant Characteristics: Pseudonym, Gender, Level of Care, and Relationship to Care Recipient

Pseudonym	Gender	Level of caregiving	Relationship to Care Recipient
Janie	Female	Secondary caregiver	Niece
Charles	Male	Primary caregiver	Husband
Rosa	Female	Primary caregiver	Wife

Categories

Fourteen categories were identified by grouping the codes together. The fourteen categories included behaviors, coping, ADL/IADL abilities, support, challenges with support and resources, you neglect yourself, self-care, keep normal as possible, stressors, level of supervision, who they were, medical problems other than dementia, and skilled services. These categories were then reduced to three themes using the common ideas and situations stated by the participants. The three themes that were identified were bad days are rough, little damper on everybody, and we try to keep normal. Each theme is described below, with participant quotations for support and a visual diagram.

Themes

Bad Days are Rough: Burdens and Strategies to Cope

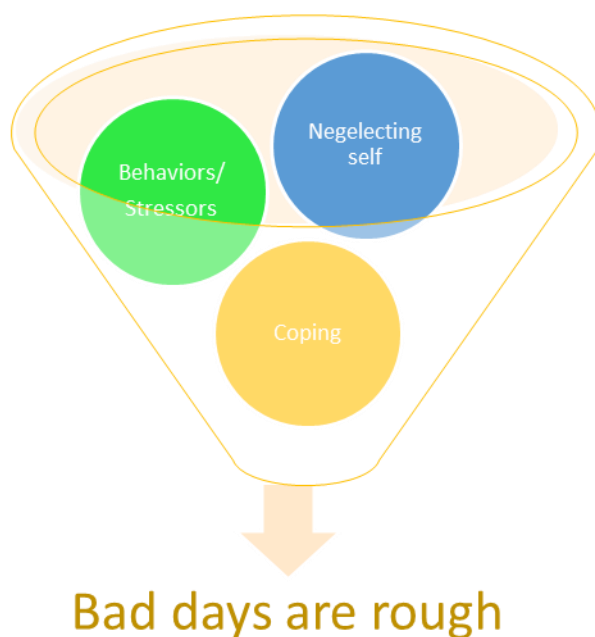
This theme was taken from a quote by Janie. This theme explained the caregivers' stressors, behaviors such as self-neglect, and the strategies they used to cope (see Figure 1). Janie explained, "on her bad days it is rough. She will curse everybody; of course, everybody is wrong." Janie's explanation of the bad days caused her to question the person she used to know versus the person with dementia she cared for. Janie stated, "these bad days are like, who is this person?" For each of the participants, bad days referred to behaviors and stressors and their attempt to cope with the changes they were facing. Charles attempted to cope with a problem his wife with dementia was having related to her toileting by going to an herb shop and subsequently giving his wife peptide shots. Charles stated, "The guy at the herb shop is trying his best to figure out what in the world is attacking her brain...we're doing things called peptides, which is a new thing, which is a shot." Charles explained "I think it has helped her. She had a problem with going to the bathroom. She'd hold it, hold it, hold it and then all of sudden she goes screaming and hollering uh oh let's get her to the bathroom, so we get her to the bathroom. Sometimes we make it. Sometimes we didn't." Rosa also identified bathroom-related stressors. She related that he must:

"use the bathroom quite a few times, but then when he finishes, he doesn't wanna come back, get in the bed. He rearranged everything in my bathroom, all the towels and the little closet here. I had to finally take all the towels. Like I said, he has all the towels out and then unfolded them. Now it's a closet right here where the bathroom is. He will have taken clothes out of the closet, and I don't know why he does that."

Rosa explained the bathroom problem happened at night so “I don’t get any sleep at night.” Although each participant tried to make sense of and cope with the changes of their care recipient, the burden of caregiving equated to challenging days.

Because of the stressors and behaviors faced by the caregivers, they neglected to take care of themselves. Rosa reported she became ill because she had not taken care of herself. “I ended up going to the emergency room. Yeah. So sometimes you kind of neglect yourself when you're trying to take care of another person.” Rosa realized she had not been taking good care of herself. Janie also reported a change in her health due to the stressors of caregiving. Janie explained that since her aunt’s dementia diagnosis she had to start taking blood pressure pills. “I think I had to get some pills to take. Since she got this ran my blood pressure up.”

Figure 1. Components of Bad Days are Rough



Little Damper on Everybody: Depressing, Subduing, and Inhibiting Effect of Caregiving and the Dementia

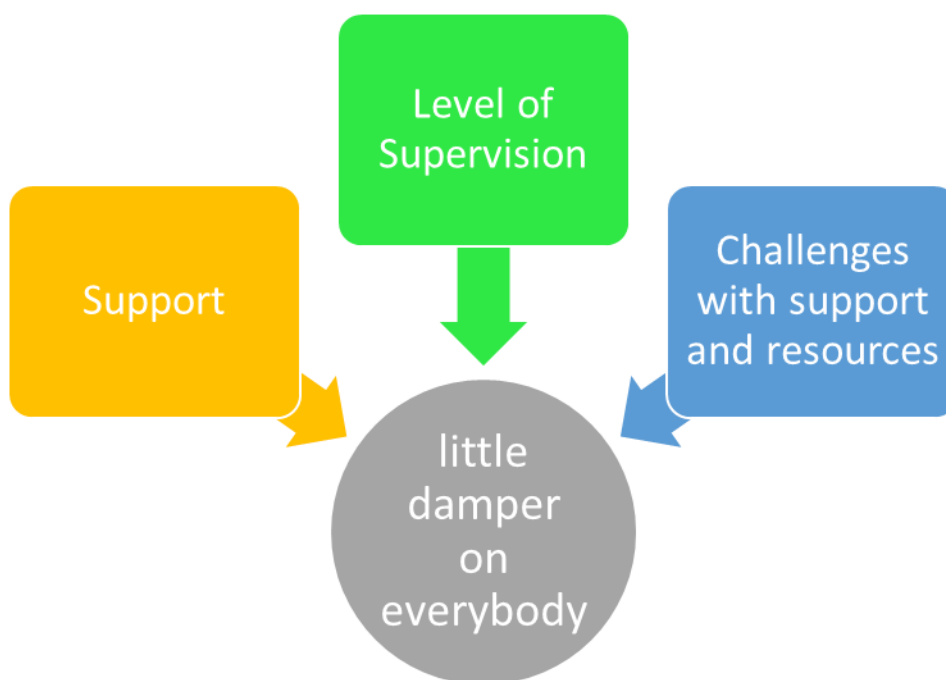
This theme was based on the depressing, subduing, and inhibiting effects of caregiving and/or the impact of dementia on the care recipient. This theme demonstrates how levels of supervision and challenges with support and resources placed a damper on the caregiver and /or care recipient (see Figure 2).

Janie noted that her aunt did not want to leave her home but could not be left alone. Janie explained, “She wants to stay in her own house, and you know you don't want to argue with her. But you know the mind is sick. So that's kind of put a little damper on everybody's schedule and a lot of things because you don't want her to be there by yourself, but you know, you gotta do we gotta do.” This quote provides insight as to how the care recipients wants and needs changed the caregiver's lifestyles because of the high level of supervision needed and the resistance of her aunt to leave her home.

Each participants' care recipient in this study was at a different stage of dementia and required different levels of care and support. Janie's aunt was diagnosed about two years ago and she was in the early stage of dementia, whereas Charles' wife was in the later stages. He was questioning himself about his wife's next level of care. Charles explained: “the question is in my mind, when do I pull the trigger, when it's time for her to go to a facility.” During this interview Charles's wife was present and although her speech was unintelligible at times, she responded to his statement by expressing her disapproval stating “NO!” This statement and her response expressed the damper on their relationship to have to contemplate this decision and possibly execute it. Charles was assessing the support and supervision his wife needed and the need for resources to help him with this decision. Rosa's husband had been diagnosed for 13 years and

she retired to take care of him. She stated, “I got the diagnosis in 2010” and “actually retired in 2013 because of his health.” Rosa explained the reason for her decision to retire. “He would keep calling me at work. He wouldn't remember that he had called me. I was eligible to retire in 2013, so I decided I opted to go ahead and retire.” This decision was also because she did not have any family support due to distance, so she was the sole caregiver with eleven hours of respite care from Veteran Affairs (VA) a week. Rosa looked forward to her eleven hours but at times she did not get it. Rosa stated “11 hours, I have to use them, so if I don't use them that week, I lose them and even if it's their fault, then I don't get a caregiver, which I don't think is fair. I look forward to that. You know, I look forward to the getting out and having a break and about an hour before this time I get a call saying that someone called in sick and they're looking for somebody else for me.” Rosa hoped for a break, but her plans were short-lived at times secondary to staffing problems with the agency. Each expressed how support, level of supervision or challenges with support and resources placed a damper on their decisions and lives.

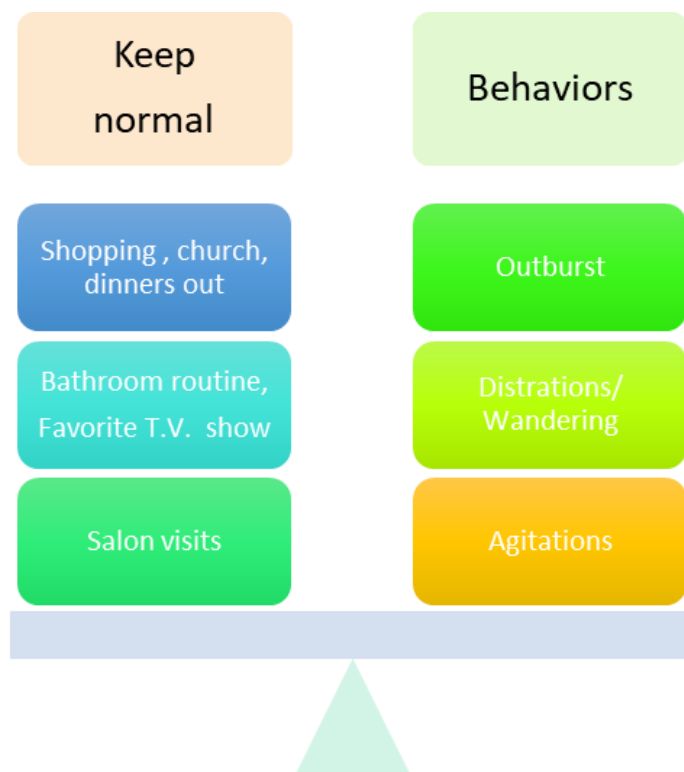
Figure 2. Components of Little Damper on Everyone



We Try to Keep Normal: Maintaining Habits and Routines

The participants and care recipients attempted to maintain habits and routines. Janie explained that her aunt's agitation had increased but they were trying to keep her normal routine of dinners out, and beauty salon visits. Janie explained, "she's been very agitated lately, so we try to keep normal, you know when the family go out to dinner. We don't. We don't leave her home. We make sure she goes with us wherever we go, or they still go to the hairdresser and get her hair done you know they still treat them some kind of some normal." The participants tried their best to keep normal activities to keep the care recipients calm and her behaviors to a minimum. Charles explained, "When we go out, she's calm as cucumber. We go out to eat, we go to church, we go grocery store or when her daughter takes her shopping, or they go get the fingernails and toenails done she does good. She had a haircut yesterday, the sitter said. She was a little talkative, but outside of that she was OK." On the other hand, Rosa's husband was in the later stages of dementia, so she was unable to manage him outside in the community. Rosa kept him normal by allowing him to perform basic ADLs with the help of him watching his favorite television shows. Rosa explained proudly that, "He does pretty good about going to the bathroom washing his hands when he finishes, but then he won't come out of the bathroom." Rosa was asked during the interview how she is dealing with the changes, and she responded, "Thankfully he watches TV." The participants quest to maintain normal routines and habits were to combat behaviors and challenges by care recipients.

Figure 3. Components of We Try to Keep Normal



Discussion

This study explored how informal caregivers of people with ADRD experience stress, and which supports help to mitigate the effects of these stressors. Based on the MOHO framework each caregiver had the desire to keep their care recipient at home (volition), and felt they had the capacity to perform their caregiver task. The challenge was their previous habits and routines had changed, which caused stress. The lack of congruence of the caregiver expectation and their reality of caregiving was in conflict which caused stress (Cheung & Fung, 2020). The study found that each caregiver experienced stress due to behaviors and changes in lifestyle which resulted in bad days and neglecting themselves. Although each caregiver faced different challenges, they all strived to keep some normalcy and use the resources they had on hand. All participants agreed they had limited healthcare guidance or referral to resources on how to manage themselves or their care recipient with dementia.

The Experience of Caregiver Stress

Neuropsychiatric symptoms are reported to cause a considerable amount of burden to caregivers, which was consistent the findings of this study (Connors et al., 2020). The caregivers of this study reported experiencing agitation, aggression, apathy, and sleep disorders that caused increased burden. Two of the three participants reported physical illness. One of the participants reported a new diagnosis of hypertension with medication and the other reported an episode of respiratory problems with difficulty breathing. Both participants related their condition to the stress of caregiving. In previous research caregivers' stress was related to increased physical symptoms, taking more medication, more hospitalization, and a greater mortality rate (Connors et al., 2020; Shoukr et al., 2022). Both female participants reported physical illness because of caregiving. The male participant reported neuropsychiatric symptoms, but he did not report any physical illness or health problems related to caregiving, which was consistent with other research that reported female caregiver experienced more burden and stress than males (Baker & Robertson, 2008). Although research states that neuropsychiatric symptoms and ADL/IADL are associated with greater caregiver burden (Cheng, 2017; Connors et al., 2020; Feast et al., 2016; Schoenmakers et al., 2010; van der Lee et al., 2014), in this study the decline in ADLs/IADLs were not reported to be the cause of stress. Janie's major stressor was her aunt's desire to drive, access to the car keys, and their lack of sleep at night. Rosa's major stressor was that her husband wandered and moved items, and their lack of sleep at night. Charles' major stressors were that his wife would hold her bowel and bladder, delusions that someone took her daughter, and her agitation. This study was consistent with other research that reported behaviors increased caregiver burden more than decreased functional abilities (Allen et al., 2020).

Each of the care recipients in this study required 24/7 supervision although they were at different stages of dementia. In previous research twenty-four-hour supervision was reported to place strains on caregivers and limit caregivers' social activities (Contreras et al., 2022). The participants in this study reported changes in lifestyle such as not being able to participate in social events. The spousal participants reported a change in social participation and the inability to socialize outside of caring for loved ones.

Caregiver Coping Strategies

The participants took on the responsibility of caregiving as an expression of their love and duty to keep their loved one's home. Greene and Smith (2019) reported that people provide care out of love, reciprocity, duty, obligation and to prevent institutionalization. Caregivers face the challenges to balance their life, care recipients' behaviors, care safety and all while trying to sustain a quality of life for them both. Coping strategies can help to mediate or manage the impact of caregiving (Lloyd et al., 2019). In this study each participant strived to cope in their own way. Coping strategies are personal and reflect the caregiver's characteristics and relationship with the care recipient (Lloyd et al., 2019).

Although coping strategies are personal, this study reviewed four coping strategies used by other studies in relation to how caregivers coped. The four categories that were used to classify caregivers' coping strategies were: emotional-focused, problem-focused, engagement, and disengagement (Balbim et al., 2019). One of the most obvious challenges that the participants in this study were coping with was the loss of the relationship and person they used to be, in which each participant was using problem-focused strategies. Problem-focused strategies are when caregiver attempts to change a situation for the better by alternative solutions, planning tasks to solve problems or circumvent stressors (Lloyd et al., 2019). Each

participant would attempt to use things, places, or entertainment to bring some sense of normalcy. Janie allowed her aunt to keep her positions at the church with supervision; Charles was relying on the herb shop clerk to diagnosis what was attacking his wife's brain; and Rosa would engage her husband in conversations because he used to do amateur radio. Each participant tried a method to keep the care recipient more like the person they used to be, because the loss can be stressful and detrimental to their physical and psychological well-being (Lloyd et al., 2019).

Caregiver Support System

Previous research reported that caregivers require information about dementia, social and emotional support from health, social, financial, and legal systems (Lauritzen et al., 2022; World Health Organization, 2012). The support systems of the participants in this study varied. Janie was a secondary caregiver that offered support to the primary caregiver two to three days a week or as needed. Charles received 40 hours of formal sitting services with periodic assistance from stepdaughter for him to hunt, and Rosa received 11 hours of respite a week from the VA with inconsistent support from family. Each participant reported some type of respite care but little information on ADRD except for the diagnosis and prognosis. One participant reported she could take courses online to learn more about ADRD, but she did not have the time. Research states that unmet needs of the caregiver results in decrease motivation to provide care as well as poor physical and psychological health (Lauritzen et al., 2022; Miranda-Castillo et al., 2013; Pini et al., 2018). The participants in this study were already having symptoms of physical health problems. The participants relied on the primary physician to diagnose and educate them but when they did not get information from their primary physician they relied on family and friends for information. Other research has reported that support is essential to the wellbeing of

caregivers and support is multifaceted from various sources such as healthcare agencies, facilities staff, Alzheimer’s Association, religious organizations, support groups, family, and friends (Donovan & Corcoran, 2010; Edwards, 2015; Hasselkus & Murray, 2007).

Table 2 summarizes the caregivers’ major stressors, primary coping strategy, support system, and skill services received. None of the caregiver recipients were receiving OT services.

Table 2. Caregivers’ Experience with Behaviors/Stress, Coping Strategies, Support and Skilled Services

Participant	Janie	Charles	Rosa
Type of Caregiver	Secondary	Primary	Primary
Major Stressors/ Behaviors of Care Recipients	<ul style="list-style-type: none"> • Driving • Having access to car keys • Sleepless nights 	<ul style="list-style-type: none"> • Agitation • Holding bowel and bladder • Hallucinations 	<ul style="list-style-type: none"> • Wandering • Moving/ hiding items • Tearing paper • Sleepless nights
Primary Coping Strategy	Emotion-focused	Problem-focused	Emotion focused
Support System	<ul style="list-style-type: none"> • Primary caregiver • Church community 	<ul style="list-style-type: none"> • 40 hours of respite/ week • Periodic support from stepdaughter 	<ul style="list-style-type: none"> • Paid caregiver 11 hours/ week • Inconsistent family support
Skilled Services	No occupational therapy	No occupational therapy.	Eval only non-related to dementia

Implications for Occupational Therapy

Occupational therapy can be instrumental in assisting caregivers and care recipients to have a better quality of life. The Occupational Therapy practice framework: Domain and Process (4th ed.; AOTA, 2020) stated that “Occupational therapy core belief in positive relationship between occupation and health and its view of people as occupational being.” Whereas caregivers of people with dementia are at an increased risk of occupational imbalance, occupational therapists are the perfect discipline to educate and assist caregivers on how to achieve occupational balance. Occupational therapists are able to assist the caregivers and care

recipients with training, on terminology, assistive technology, modification, behavior modification and guidance for finding and seeking help, relaxation techniques, stress management, and identifying caregiver's burnout (Edwards, 2015). These interventions and resources would have been beneficial to these caregivers if they were referred to OT.

Occupational therapy could have helped them mitigate their stressors, but the caregivers were not aware of or referred to OT, congruent with other research in which OT is not a referred service for clients and families with ADRD. OTs need to be more of an advocate for early referral to services (Edwards, 2015; Graff et al., 2008). With so many caregivers of persons with ADRD experiencing occupational imbalance and there being a documented need increased early intervention services, there is a service gap in which occupational therapy services could help fill.

Make implications for future research and clinical practice to advocate for what you wrote above.

Limitations

This was a small study to explore how informal caregivers of a person with ADRD experience stress and which supports help mitigate the effect of these stressors in their role as a caregiver. The results are not intended to generalize all caregivers but to better understand the lived experiences of people with ADRD caregivers and their challenges. The findings of this study were consistent with other studies which explored the caregiver challenges with care recipient's behaviors, lack of support and loss of the person they used to be caused caregiver burdens. There needs to be further information on primary care physician's referral procedures and their understanding of OT and how OT can be a benefit to people with ADRD and their

caregivers. People with ADRD and their caregivers are relying on the primary care physician for information and there is a need for a more efficient referral system to better serve these clients.

The timing and in-depth interviews was another limitation. Two out of three caregivers had to perform the interview while attending to their care recipients. In one interview, the care recipient sat in on the interview, this limited the PI's ability to ask in depth questions out respect and dignity for the care recipient. It is possible that the caregiver filtered his response and limited the in-depth response because his wife was present.

Conclusion

This study explored the experiences of caregivers of people with ADRD stress and what supports helped them to cope and decrease their burdens. The participants' stressors were consistent with other studies that stated behaviors cause increased burden on caregivers. Although there are programs and assistance for caregivers, there is a deficit in caregivers' referrals to resources and OT. The caregivers are relying on their primary health care provider for guidance and the systems are faulty. Occupational therapists must advocate to bring awareness on their benefits to people with ADRD and their caregivers to bridge the gap and help these clients live a quality of life.

References

- 2021 Alzheimer's disease facts and figures. (2021). *Alzheimer's & Dementia*, 17(3), 327–406.
<https://doi.org/10.1002/alz.12328>
- Allen, A. P., Buckley, M. M., Cryan, J. F., Ní Chorcoráin, A., Dinan, T. G., Kearney, P. M., O’Caoimh, R., Calnan, M., Clarke, G., & Molloy, D. W. (2020). Informal caregiving for dementia patients: The contribution of patient characteristics and behaviours to caregiver burden. *Age and Ageing*, 49(1), 52–56. <https://doi.org/10.1093/ageing/afz128>
- Ahn, M., Kang, J., & Kwon, H. (2019). The Concept of Aging in Place as Intention. *The Gerontologist*. <https://10.1093/geront/gny167>
- American Occupational Therapy Association. (2020). Occupational therapy practice framework: Domain and process (4th ed.). *American Journal of Occupational Therapy*, 74(Suppl. 2), 7412410010. <https://doi.org/10.5014/ajot.2020.74S2001>
- Angeles, R. C., Berge, L. I., Gedde, M. H., Kjerstad, E., Vislapuu, M., Puaschitz, N. G., & Husebo, B. S. (2021). Which factors increase informal care hours and societal costs among caregivers of people with dementia? A systematic review of Resource Utilization in Dementia (RUD). *Health Economics Review*, 11(1), 37.
<https://doi.org/10.1186/s13561-021-00333-z>
- Ávila, A., De-Rosende-Celeiro, I., Torres, G., Vizcaíno, M., Peralbo, M., & Durán, M. (2018). *Health & Social Care in the Community*, 26(5), 734–743.
<https://doi.org/10.1111/hsc.12594>
- Baker, K. L., & Robertson, N. (2008). Coping with caring for someone with dementia: Reviewing the literature about men. *Aging & Mental Health*, 12(4), 413–422.
<https://doi.org/10.1080/13607860802224250>

- Balbin, G. M., Marques, I. G., Cortez, C., Magallanes, M., Rocha, J., & Marquez, D. X. (2019). Coping strategies utilized by middle-aged and older Latino caregivers of loved ones with Alzheimer's disease and related dementia. *Journal of Cross-Cultural Gerontology*, *34*(4), 355–371. <https://doi.org/10.1007/s10823-019-09390-8>
- Brandão, D., Ribeiro, O., & Martín, I. (2016). Underuse and unawareness of residential respite care services in dementia caregiving: Constraining the need for relief. *Health & Social Work*, *41*(4), 254–262. <https://doi.org/10.1093/hsw/hlw041>
- Cheng, S.-T. (2017). Dementia caregiver burden: A research update and critical analysis. *Current Psychiatry Reports*, *19*(9), 64. <https://doi.org/10.1007/s11920-017-0818-2>
- Cheung, P., & Fung, Xavier C. C. (2020). A review on the case studies of using the model of human occupation. *Social Health and Behavior*, *3*(1), 3. https://doi.org/10.4103/SHB.SHB_49_19
- Cole, M., & Tufano, Roseanna. (2020). *Applied Theories in Occupational Therapy: A practical approach* (2nd ed.). SLACK Incorporated.
- Collins, R. N., & Kishita, N. (2020). Prevalence of depression and burden among informal caregivers of people with dementia: A meta-analysis. *Ageing and Society*, *40*(11), 2355–2392. <https://doi.org/10.1017/S0144686X19000527>
- Connors, M. H., Secher, K., Teixeira-Pinto, A., Woodward, M., Ames, D., & Brodaty, H. (2020). Dementia and caregiver burden: A three-year longitudinal study. *International Journal of Geriatric Psychiatry*, *35*(2), 250–258. <https://doi.org/10.1002/gps.5244>
- Contreras, M., Mioshi, E., & Kishita, N. (2022). What are the educational and support needs of family carers looking after someone in the early stages of Alzheimer's disease? A

- qualitative retrospective approach. *Health & Social Care in the Community*, 30(5), 1726–1734. <https://doi.org/10.1111/hsc.13552>
- Creswell, J., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches* (5th ed.). SAGE edge.
- Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry & research design: Choosing among five approaches* (Fourth edition). SAGE.
- Donovan, M. L., & Corcoran, M. A. (2010). Description of dementia caregiver uplifts and implications for occupational therapy. *American Journal of Occupational Therapy*, 64(4), 590–595. <https://doi.org/10.5014/ajot.2010.09064>
- Dooley, N. R., & Hinojosa, J. (2004). Improving quality of life for persons with Alzheimer's disease and their family caregivers: Brief occupational therapy intervention. *American Journal of Occupational Therapy*, 58(5), 561–569. <https://doi.org/10.5014/ajot.58.5.561>
- Edwards, M. (2015). Family caregivers for people with dementia and the role of occupational therapy. *Physical & Occupational Therapy In Geriatrics*, 33(3), 220–232. <https://doi.org/10.3109/02703181.2015.1031926>
- Engel, L., Loxton, A., Bucholc, J., Muldowney, A., Mihalopoulos, C., & McCaffrey, N. (2022). Providing informal care to a person living with dementia: The experiences of informal carers in Australia. *Archives of Gerontology and Geriatrics*, 102, 104742. <https://doi.org/10.1016/j.archger.2022.104742>
- Feast, A., Moniz-Cook, E., Stoner, C., Charlesworth, G., & Orrell, M. (2016). A systematic review of the relationship between behavioral and psychological symptoms (BPSD) and caregiver well-being. *International Psychogeriatrics*, 28(11), 1761–1774. <https://doi.org/10.1017/S1041610216000922>

- Graff, M. J. L., Adang, E. M. M., Vernooij-Dassen, M. J. M., Dekker, J., Jönsson, L., Thijssen, M., Hoefnagels, W. H. L., & Rikkert, M. G. M. O. (2008). Community occupational therapy for older patients with dementia and their care givers: Cost effectiveness study. *BMJ*, *336*(7636), 134–138. <https://doi.org/10.1136/bmj.39408.481898.BE>
- Graff, M. J. L., Vernooij-Dassen, M. J. M., Thijssen, M., Dekker, J., Hoefnagels, W. H. L., & Rikkert, M. G. M. O. (2006). Community based occupational therapy for patients with
- 2021 Alzheimer's disease facts and figures. (2021). *Alzheimer's & Dementia*, *17*(3), 327–406. <https://doi.org/10.1002/alz.12328>
- Greenwood, N., & Smith, R. (2019). Motivations for being informal carers of people living with dementia: A systematic review of qualitative literature. *BMC Geriatrics*, *19*(1), 169. <https://doi.org/10.1186/s12877-019-1185-0>
- Harrison, S. L., Lang, C., Whitehead, C., Crotty, M., Corlis, M., Wesselingh, S., & Inacio, M. C. (2020). Residential Respite Care Use Is Associated With Fewer Overall Days in Residential Aged Care. *Journal of the American Medical Directors Association*, *21*(5), 653-659.e2. <https://doi.org/10.1016/j.jamda.2019.08.023>
- Lloyd, J., Muers, J., Patterson, T. G., & Marczak, M. (2019). Self-Compassion, Coping Strategies, and Caregiver Burden in Caregivers of People with Dementia. *Clinical Gerontologist*, *42*(1), 47–59. <https://doi.org/10.1080/07317115.2018.1461162>
- Mills, A. J., Durepos, G., & Wiebe, E. (n.d.). *Encyclopedia of case study research*. SAGE.
- Morimoto, H., Furuta, N., Kono, M., & Kabeya, M. (2019). Stress-buffering Effect of Coping Strategies on Interrole Conflict among Family Caregivers of People with Dementia. *Clinical Gerontologist*, *42*(1), 34–46. <https://doi.org/10.1080/07317115.2017.1368764>

- Office of Disease Prevention and Health Promotion. (n.d.). *Healthy People 2030* [Government].
U.S. Department of Health and Human Services.
<https://health.gov/healthypeople/objectives-and-data/browse-objectives/health-communication/decrease-proportion-adults-who-report-poor-communication-their-health-care-provider-hchit-02>
- Oken, B. S., Fonareva, I., & Wahbeh, H. (2011). Stress-Related Cognitive Dysfunction in Dementia Caregivers. *Journal of Geriatric Psychiatry and Neurology*, *24*(4), 191–198.
<https://doi.org/10.1177/0891988711422524>
- Phan, S. V., Osa, S., Morgan, J. C., Inyang, M., & Fagan, S. C. (2019). Neuropsychiatric Symptoms in Dementia: Considerations for Pharmacotherapy in the USA. *Drugs in R&D*, *19*(2), 93–115. <https://doi.org/10.1007/s40268-019-0272-1>
- Piersol, C. V., Canton, K., Connor, S. E., Giller, I., Lipman, S., & Sager, S. (2017). Effectiveness of Interventions for Caregivers of People With Alzheimer’s Disease and Related Major Neurocognitive Disorders: A Systematic Review. *The American Journal of Occupational Therapy*, *71*(5), 7105180020p1-7105180020p10.
<https://doi.org/10.5014/ajot.2017.027581>
- Pöysti, M. M., Laakkonen, M.-L., Strandberg, T., Savikko, N., Tilvis, R. S., Eloniemi-Sulkava, U., & Pitkälä, K. H. (2012). Gender Differences in Dementia Spousal Caregiving. *International Journal of Alzheimer’s Disease*, *2012*, 1–5.
<https://doi.org/10.1155/2012/162960>
- Raj, S. E., Mackintosh, S., Fryer, C., & Stanley, M. (2021). Home-Based Occupational Therapy for Adults With Dementia and Their Informal Caregivers: A Systematic Review. *The*

- American Journal of Occupational Therapy*, 75(1), 7501205060p1-7501205060p27.
<https://doi.org/10.5014/ajot.2020.040782>
- Schoenmakers, B., Buntinx, F., & Delepeleire, J. (2010). Factors determining the impact of care-giving on caregivers of elderly patients with dementia. A systematic literature review. *Maturitas*, 66(2), 191–200. <https://doi.org/10.1016/j.maturitas.2010.02.009>
- Shoukr, E. M. M., Mohamed, A. A. E.-R., El-Ashry, A. M., & Mohsen, H. A. (2022). Effect of psychological first aid program on stress level and psychological well-being among caregivers of older adults with alzheimer’s disease. *BMC Nursing*, 21(1), 275.
<https://doi.org/10.1186/s12912-022-01049-z>
- Sultana, R., & Agius, A. (2019). Pathways to residential respite care in Malta: A qualitative study. *International Journal on Aging in Developing Countries*, 4(2), 91–107.
- Taylor, R. R. (2017). *Kielhofner’s research in occupational therapy: Methods of inquiry for enhancing practice* (Second edition). F.A. Davis Company.
- Thinnes, A., & Padilla, R. (2011). Effect of Educational and Supportive Strategies on the Ability of Caregivers of People With Dementia to Maintain Participation in That Role. *The American Journal of Occupational Therapy*, 65(5), 541–549.
<https://doi.org/10.5014/ajot.2011.002634>
- van der Lee, J., Bakker, T. J. E. M., Duivenvoorden, H. J., & Dröes, R.-M. (2014). Multivariate models of subjective caregiver burden in dementia: A systematic review. *Ageing Research Reviews*, 15, 76–93. <https://doi.org/10.1016/j.arr.2014.03.003>
- Vandepitte, S., Van Den Noortgate, N., Putman, K., Verhaeghe, S., Verdonck, C., & Annemans, L. (2016). Effectiveness of respite care in supporting informal caregivers of persons with dementia: A systematic review: Impact of dementia respite care in supporting caregivers.

International Journal of Geriatric Psychiatry, 31(12), 1277–1288.

<https://doi.org/10.1002/gps.4504>

Wylie, M. J., Kim, K., Liu, Y., & Zarit, S. H. (2021). Taking a Break: Daily Respite Effects of Adult Day Services as Objective and Subjective Time Away From Caregiving. *The Gerontologist*, 61(8), 1231–1240. <https://doi.org/10.1093/geront/gnaa178>

dementia and their care givers: Randomised controlled trial. *BMJ*, 333(7580), 1196.

<https://doi.org/10.1136/bmj.39001.688843.BE>

Harrison, S. L., Lang, C., Whitehead, C., Crotty, M., Corlis, M., Wesselingh, S., & Inacio, M. C. (2020). Residential respite care use is associated with fewer overall days in residential aged care. *Journal of the American Medical Directors Association*, 21(5), 653-659.e2.

<https://doi.org/10.1016/j.jamda.2019.08.023>

Hasselkus, B. R., & Murray, B. J. (2007). Everyday occupation, well-being, and identity: The experience of caregivers in families with dementia. *American Journal of Occupational Therapy*, 61(1), 9–20. <https://doi.org/10.5014/ajot.61.1.9>

Kielhofner, G. & Barret, L. (1997). An overview of occupational behavior. In Hopkins & H. Smith (Eds.), *William & Spackman's occupational therapy*. Philadelphia, PA: JB Lippincott.

Lauritzen, J., Sørensen, E. E., Pedersen, P. U., & Bjerrum, M. B. (2022). Needs of carers participating in support groups and caring for a person with dementia: A focused ethnographic study. *Dementia*, 21(4), 1219–1232.

<https://doi.org/10.1177/14713012211072928>

Lloyd, J., Muers, J., Patterson, T. G., & Marczak, M. (2019). Self-compassion, coping strategies, and caregiver burden in caregivers of people with dementia. *Clinical Gerontologist*, 42(1), 47–59. <https://doi.org/10.1080/07317115.2018.1461162>

- Mills, A. J., Durepos, G., & Wiebe, E. (n.d.). *Encyclopedia of case study research*. SAGE.
- Miranda-Castillo, C., Woods, B., & Orrell, M. (2013). The needs of people with dementia living at home from user, caregiver and professional perspectives: A cross-sectional survey. *BMC Health Services Research*, *13*(1), 43. <https://doi.org/10.1186/1472-6963-13-43>
- Morimoto, H., Furuta, N., Kono, M., & Kabeya, M. (2019). Stress-buffering effect of coping strategies on inter-role conflict among family caregivers of people with dementia. *Clinical Gerontologist*, *42*(1), 34–46. <https://doi.org/10.1080/07317115.2017.1368764>
- Occupational Therapy Code of Ethics (2015). (2015). *American Journal of Occupational Therapy*, *69*(Supplement_3), 6913410030p1-6913410030p8. <https://doi.org/10.5014/ajot.2015.696S03>
- Office of Disease Prevention and Health Promotion. (n.d.). *Healthy People 2030* [Government]. U.S. Department of Health and Human Services. <https://health.gov/healthypeople/objectives-and-data/browse-objectives/health-communication/decrease-proportion-adults-who-report-poor-communication-their-health-care-provider-hchit-02>
- Oken, B. S., Fonareva, I., & Wahbeh, H. (2011). Stress-related cognitive dysfunction in dementia caregivers. *Journal of Geriatric Psychiatry and Neurology*, *24*(4), 191–198. <https://doi.org/10.1177/0891988711422524>
- Phan, S. V., Osa, S., Morgan, J. C., Inyang, M., & Fagan, S. C. (2019). Neuropsychiatric symptoms in dementia: Considerations for pharmacotherapy in the USA. *Drugs in R&D*, *19*(2), 93–115. <https://doi.org/10.1007/s40268-019-0272-1>

- Pini, S., Ingleson, E., Megson, M., Clare, L., Wright, P., & Oyebode, J. R. (2018). A needs-led framework for understanding the impact of caring for a family member with dementia. *Gerontologist, 58*(2), e68–e77. <https://doi.org/10.1093/geront/gnx148>
- Raj, S. E., Mackintosh, S., Fryer, C., & Stanley, M. (2021). Home-based occupational therapy for adults with dementia and their informal caregivers: A systematic review. *American Journal of Occupational Therapy, 75*(1), 7501205060p1-7501205060p27. <https://doi.org/10.5014/ajot.2020.040782>
- Schoenmakers, B., Buntinx, F., & Delepeleire, J. (2010). Factors determining the impact of caregiving on caregivers of elderly patients with dementia. A systematic literature review. *Maturitas, 66*(2), 191–200. <https://doi.org/10.1016/j.maturitas.2010.02.009>
- Shoukr, E. M. M., Mohamed, A. A. E.-R., El-Ashry, A. M., & Mohsen, H. A. (2022). Effect of psychological first aid program on stress level and psychological well-being among caregivers of older adults with alzheimer’s disease. *BMC Nursing, 21*(1), 275. <https://doi.org/10.1186/s12912-022-01049-z>
- Sultana, R., & Agius, A. (2019). Pathways to residential respite care in Malta: A qualitative study. *International Journal on Aging in Developing Countries, 4*(2), 91–107.
- Taylor, R. R. (2017). *Kielhofner’s research in occupational therapy: Methods of inquiry for enhancing practice* (Second edition). F.A. Davis Company.
- Vann, M. (2016, August 1) The 15 most common health concerns for seniors. Everyday Health. <https://www.everydayhealth.com/news/most-common-health-concerns-seniors/>
- van der Lee, J., Bakker, T. J. E. M., Duivenvoorden, H. J., & Dröes, R.-M. (2014). Multivariate models of subjective caregiver burden in dementia: A systematic review. *Ageing Research Reviews, 15*, 76–93. <https://doi.org/10.1016/j.arr.2014.03.003>

- Vandepitte, S., Van Den Noortgate, N., Putman, K., Verhaeghe, S., Verdonck, C., & Annemans, L. (2016). Effectiveness of respite care in supporting informal caregivers of persons with dementia: A systematic review: Impact of dementia respite care in supporting caregivers. *International Journal of Geriatric Psychiatry, 31*(12), 1277–1288.
<https://doi.org/10.1002/gps.4504>
- Wawrziczny, E., Duprez, C., & Antoine, P. (2020). Predictors of caregiver distress among spouses, adult children living with the person with dementia, and adult children not living with the person with dementia. *Psychogeriatrics, 20*(5), 594–601.
<https://doi.org/10.1111/psyg.12553>
- World Health Organization. (2012). Dementia: A public health priority https://www.who.int/mental_health/publication/dementia_report_2012/en/
- Wylie, M. J., Kim, K., Liu, Y., & Zarit, S. H. (2021). Taking a break: Daily respite effects of adult day services as objective and subjective time away from caregiving. *Gerontologist, 61*(8), 1231–1240. <https://doi.org/10.1093/geront/gnaa178>

Appendix A: Institutional Review Board Approval



Hello Kwandra Brinson,

Congratulations! Using a limited review process, the Institutional Review Board at Eastern Kentucky University (FWA00003332) has approved your request for an exemption determination for your study entitled, "How do informal caregivers of a person with Alzheimer's disease or related dementias (ADRD) experience stress and which supports help to mitigate the effects of these stressors in their role as a caregiver?" This status is effective immediately and is valid for a period of three years as long as no changes are made to the study as outlined in your limited review application. If your study will continue beyond three years, you are required to reapply for exemption and receive approval from the IRB prior to continuing the study.

As the principal investigator for this study, it is your responsibility to ensure that all investigators and staff associated with this study meet the training requirements for conducting research involving human subjects and comply with applicable University policies and state and federal regulations. Please read through the remainder of this notification for specific details on these requirements.

Adverse Events: Any adverse or unexpected events that occur in conjunction with this study should be reported to the IRB immediately and must be reported within ten calendar days of the occurrence.

Changes to Approved Research Protocol: If changes to the approved research protocol become necessary, a Protocol Revision Request must be submitted for IRB review, and approval must be granted prior to the implementation of changes. If the proposed changes result in a change in your project's exempt status, you will be required to submit an application for expedited or full review and receive approval from the IRB prior to implementing changes to the study. Changes include, but are not limited to, those involving study personnel, subjects, recruitment materials and procedures, and data collection instruments and procedures.