

CARING FOR A FAMILY MEMBER WITH DEMENTIA: AN OCCUPATIONAL
THERAPY APPROACH TO FACILITATE POSITIVE DIMENSIONS OF
CAREGIVING

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ABSTRACT

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CARING FOR A FAMILY MEMBER WITH DEMENTIA: AN OCCUPATIONAL THERAPY APPROACH TO FACILITATE POSITIVE DIMENSIONS OF CAREGIVING

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Dementia is a progressive, chronic disorder that affects 3 to 4 million individuals in the U.S. Challenges that occur as the disease progresses are: decline in cognitive functions; disruption of sleep and eating patterns; disorientation to person, place, and time; and loss of ability to understand and communicate. Due to these challenges, a person with dementia (PWD) requires more supervision and assistance to remain safe. Caregivers provide this level of supervision and assistance to the PWD. This amount of assistance can cause caregiver stress or physical or emotional strain. Caregiver stress increases when PWD exhibits challenging behaviors that manifest as part of the disease. Occupational therapy practitioners play a unique role in developing strategies for helping families effectively cope with dementia.

The purpose of this research study was to explore the benefits of caring for a person diagnosed with dementia and develop an approach for occupational therapy to facilitate possible positive dimensions of caregiving.

This research study was guided by three aims. The first aim explored caregivers' perspectives on experiences of caring for a family member with dementia. The second aim examined ways in which occupational therapy currently facilitates positive dimensions of

care by collecting data from occupational therapists by using an interview guide. The last aim was to develop an intervention protocol for occupational therapy that will help enhance positive relationships between caregiving dyad members. This protocol was developed based on the data collected from the first two aims and current best evidence. This was developed to help build a program that can assist in improving interaction between caregivers and care receivers. The occupational therapists used the AGREE II to provide feedback on the quality of interventions that were developed based on the data collected. The findings showed that the interventions used to create the caregiver intervention protocol manual can be used in clinical practice and caregiver education to improve interaction between caregiving dyad members but will require clearer stated objectives, risks, and strengths and limitations of the interventions.

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CHAPTER I

INTRODUCTION

Statement of the Problem

The challenges that caregivers of persons with dementia (PWD) experience have been the primary focus of caregiving research for years (Donovan & Corcoran, 2010). The majority of researchers focus on interventions that reduce stress, burden, or depression of caregivers. Only a minimal amount of research has focused on the positive aspects of caregiving (Donovan & Corcoran, 2010). Positive aspects related to caregiving that have been identified are spiritual and personal growth and feelings of mastery which, in turn, facilitates meaning and fulfillment in caregivers' lives (Yap, Seow, Henderson, & Goh, 2005). Since dementia research with family caregivers has primarily focused on improving quality of life, the health care experience, and negative challenges involved as the disease progresses (Porock, Horgan, & Seitz, 2013), exploration of the personal gains and benefits that come with dementia caregiving seems warranted.

The research focus of occupational therapy on caregiving has measured the effects of interventions on constructs such as quality of life and mood; but there has been no research on occupational therapy interventions that enhance caregivers' positive feelings of care (Donovan & Corcoran, 2010). The caregiving research on interventions has more to do with how caregivers compensate for cognitive decline, ease the burden of care, provide more effective supervision, and/or strengthen coping behaviors (Donovan & Corcoran, 2010).

Role of Caregivers

Occupations are central to a person's identity and sense of competence. In the American Occupational Therapy Association's Occupational Therapy Practice Framework 3rd edition (2014), the word 'occupation' is defined as everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning and purpose to a person's life. The role of caregiver is considered as a co-occupation or two or more individuals who share occupations. The role of caregiver or caregiving involves participation from both the caregiver and care recipient. (AOTA, 2014).

The role of a caregiver is to be able to problem solve, make decisions, and accept the role with well-being and satisfaction (Williams, 2016). The caregiver role has been shown to create strain and burden on a person's social, occupational, and personal roles. Recent attention and efforts to develop adequate interventions to address the burden and strain have found that if a caregiver willingly chooses to assume the role and the care recipient appreciates the care assistance provided, the role and identity of caregiver are embraced; but if the role is forced on the caregiver, or if providing care is seen as extension of one's role as a partner or child, resistance in assuming the role and identity is seen (Williams, 2016). Most caregivers who self-identify themselves in this role will find satisfaction and positive aspects of the role outweigh the negative. Increased appreciation for life, feelings of importance and usefulness, greater strength and confidence, feeling closer to the care recipient, and increased strength of the relationship

are described as part of the experience for those who are able to identify themselves as the role of caregiver (Williams, 2016).

Statement of the Purpose

The purpose of this research study was to explore the benefits of caring for a PWD and develop an approach for occupational therapy to facilitate possible positive dimensions of caregiving. The three aims that guided this research were:

- Exploring caregivers' perspectives on experiences of caring for a family member with dementia.
- Examining ways in which occupational therapy currently facilitates positive dimensions of care.
- Developing an intervention protocol for occupational therapy that will help enhance positive relationships between caregiving dyad members.

Significance of the Study

The idea of 'caregiving gain' has been explained as the ability to find meaning in a caregiver's life. By caregivers finding a new meaning, their lives acquire a new purpose. The relationships within the family are strengthened and their beliefs about the world and life take on a whole new meaning. The process of finding meaning or seeing the positive is a choice that caregivers can make. Spiritual growth, personal growth, and feelings of mastery are the gains that can be experienced by dementia caregivers. The idea that positive outcomes do emerge from the caregiving role certainly justifies further study (Yap et al., 2005).

Occupational therapy practitioners are in a unique position to assist families to: understand the dementia disease process; modify daily routines; provide training on strategies to manage difficult behaviors; and teach family caregivers ways to reduce their own stress and take care of themselves. Evidence-based practical approaches help caregivers manage the care for people with dementia (Piersol, Earland, & Herge, 2012). Yet, the emphasis is on relieving burden of care and reducing stress, rather than focusing on the positive outcomes that may be possible in such care management interactions.

The significance of this research study is to understand the ways in which occupational therapy can play a role in family caregiving to those who are dealing with a family member diagnosed with dementia. Developing an approach for occupational therapy practitioners that provide effective interventions to facilitate positive feelings of caregiving will help to maintain positive relationships between caregiving dyad members and, in turn, reduce the stress of caregiving.

Theoretical Framework for Study: Person-Environment-Occupation (PEO) Model

Activities that relate to one's life roles can be defined as those used to engage in occupation. Engagement in occupation plays a significant role in a person's health and well-being. Many older people have expressed that being involved in a specific role in society or family and to perform activities related to life roles are central to one's quality of life. Research has shown that people with advanced dementia still have an innate need for participation in activities. The progressive levels of cognitive and functional limitations experienced by (PWD) restrict their engagement in meaningful activities.

PWD rely on caregivers for the performance of many activities such as daily tasks and socially related activities (Tsunaka & Chung, 2012).

The Person-Environment-Occupation (PEO) model is the conceptual model for this research study. The PEO model is composed of three main components: Person, Environment, and Occupation. The person is a unique being who assumes variety of roles and is seen holistically as a composite of mind, body, and spiritual qualities, who is constantly interacting with the environment. The environment is defined as encompassing the cultural, socio-economic, institutional, physical, and social dimensions. The occupation refers to activities and tasks performed by the person in relation to his or her life roles (Tsunaka & Chung, 2012). According to the PEO model, occupational performance or the doing of occupation or activities to satisfy one's needs, emerges from the interaction of the person with his occupations and with the environments in which he or she lives, works, and plays. Occupational performance is maximized when there is optimal fit between the components. With disease progression or increasing cognitive difficulties, engagement in previous activities is deterred. The PEO model provides a systematic approach to analyze the person's function and dysfunction and how social and living environments and occupational activities can be adapted to promote optimal and safe occupational performance (Tsunaka & Chung, 2012).

Researcher's Perspective

I have had an interest in the area of dementia for a very long time, but my interest has grown stronger over the last several years. The reason for this strong interest is

because, as a traveling occupational therapist, the majority of the patients whom I've seen had dementia. I've worked in several skilled nursing and inpatient rehab facilities. At least 50% of patients in skilled nursing and inpatient rehab facilities had some level of dementia. There are several challenges that I have experienced as an occupational therapist when treating patients with dementia. One challenge is communication or being able to keep my verbal instructions as basic or simple as possible so PWD can understand and perform functional tasks the best way they know how. But, the most challenging issue is trying to help the caregivers. What we as occupational therapists must realize is that caregivers are providing round the clock care to their family members with dementia. Caregivers rarely have any breaks or time for themselves; there is no caregiver or life balance. Many times I have talked with caregivers on how their family members are doing in therapy regarding functional gains or discharge recommendations; but most of the time they were so overwhelmed, to the point they would breakdown and cry. When working in inpatient rehab facilities, I have requested family conferences with caregivers of patients with dementia. The reason for these family conferences is to discuss the patient's progress and discharge recommendations. The multidisciplinary team may either recommend a skilled nursing facility or memory home. When caregivers hear these specific recommendations, they start to feel a sense of regret or guilt. The caregivers want to place their family member in one of the facilities per recommendation so that they can feel a sense of freedom; but they are apprehensive because they do not want to feel guilty or have their loved ones resent them. As occupational therapists, we provide education on discharge disposition for the clients and a rationale for the recommendations being made.

However, we seem to have difficulty providing education on interventions that might help caregivers find a life balance and facilitate positive feelings towards caring for their loved ones, instead of feeling stress. The intent of this research study, then, was to develop an intervention protocol that facilitates positive feelings of caregiving and helps maintain positive relationships between caregivers and their family members with dementia.

CHAPTER II

BACKGROUND AND SIGNIFICANCE

Dementia is a progressive, chronic disorder that affects 3 to 4 million individuals in the U.S. In 2005, it was reported that 24.3 million people worldwide have some form of dementia, and the number of new cases will double every 20 years (Liew et al., 2010) Dementia is the leading cause of dependency and disability among older people (Nyman & Szymczynska, 2016). There are several challenges that can occur as dementia develops. These challenges include: decline in cognitive functions and judgment; disruption of sleep and eating patterns; disorientation to person, place, and time; and loss of ability to understand and communicate (Thinnes & Padilla, 2011). Because of these specific challenges, a person with dementia requires more frequent supervision to remain safe (Thinnes & Padilla, 2011).

In 2013, 5.3 million individuals with dementia and Alzheimer's disease in the US were cared for by 15.4 million family caregivers who provided 17.5 billion hours of unpaid help (Gaugler, Hobday, Robbins, & Barclay, 2015). Caregivers remain in their role for extended periods of time even when engaged in other activities. They commit vast quantities of time and money to the task (Ostwald, Hepburn, Caron, Burns, & Mantell, 1999). Caregivers have been in their role for an average of 4.6 years (National Alliance for Caregiving, 2009). They average 20.4 hours per week with three in ten who

have provided care to someone with dementia for five or more years (National Alliance for Caregiving, 2009).

Early-Onset vs. Late-Onset Dementia

People with early-onset dementia may function independently. They may still drive, work, and be part of social activities. Although they are functional, they may feel as if they are having memory lapses such as forgetting familiar words or the location of everyday objects. Common difficulties that are seen with early-onset dementia are: problems coming up with the right word or name; trouble remembering names when introduced to new people, challenges performing tasks in social or work environment; forgetting material that one has just read; losing or misplacing a valuable object; and/or increasing trouble with planning and organizing (Alzheimer's Association, 2017). Other common problems seen in early-onset dementia are problems with movement, coordination, walking, and balance. Early-onset is more likely to be hereditary. Ten percent of people with early-onset dementia seems to have inherited the disease from a parent (Alzheimer's Society, 2015). The main caregiver of a person with early-onset dementia is more likely to have a longer duration of caregiving, has less social support, takes on higher degree of burden and suffers from more symptoms of depression (Kimura, Maffioletti, Santos, Baptista, & Dourado, 2015).

Late-stage dementia causes people to lose the ability to respond to their environment, to carry out conversations, and eventually to control movement. In this stage, communicating pain becomes difficult. As the memory and cognitive skills worsens, personality changes may take place and individuals need extensive help with

daily tasks. (Alzheimer's Association, 2017). With late-stage dementia, people may need 24/7 assistance with daily tasks; lose awareness of recent experiences as well as surroundings; experience changes in physical abilities; have increase difficulty communication; and become vulnerable to infections (Alzheimer's Association, 2017). During this stage, the caregiver focuses on preserving dignity and quality of life. In this stage, people typically loses the ability to talk and express needs. Research says that some core of the person's self may remain. This means the caregiver may be able to continue to connect throughout the late-stage dementia. During this stage, the world is primarily experienced through senses. Caregivers can express caring through touch, sound, sight, taste, and smell. Some examples are: playing their favorite music, preparing favorite food, brushing the care recipient's hair, and/or siting outside together on a nice day (Alzheimer's Association, 2017).

Types of Caregivers

There are two types of caregivers: formal or paid and informal or unpaid. Formal and informal caregivers may provide care to a person with dementia. Around 70% of people with dementia live at home and are cared by informal caregivers or relatives and friends. These caregivers are comprised of about 60% women age 55 or older, married, and have less than a college degree. More than half of the caregivers are the primary breadwinners of the household and nearly half are employed full or part time outside of the home (Piersol et al., 2012). Dyadic relationships take on new roles and meanings with potentially adverse outcomes as dementia care progresses (Fauth et al., 2012).

The Stress Process Model

The Stress Process Model is a framework that explains caregiver burden in long term care studies. The Stress Process Model explains that primary and secondary stressors affect caregiver mental health outcomes. Psychosocial resources can influence the effect of the primary and secondary stressors on caregiver health status. Secondary stressors in the Stress Process Model refer to stressful experiences triggered by primary stressors. Primary stressors are identified as the level of care needed by the care recipient and the extent and type of caregiving involvement by the caregiver. Cognitive impairments, problematic behaviors, and functional limitations are characteristics of primary stressor in the care recipient. Caregivers who performed frequent personal care reported lower subjective burden and those who provided more instrumental care led to a higher subjective burden (Liu & Bern-Klug, 2016). Lui & Bern-Klug (2016) explain the reason behind the higher subjective burden while providing assistance with instrumental care may be related to caregivers not making the necessary adjustments at home and at work to accommodate the caregiving role, whereas by the time the caregiver is assisting with activities of daily living or ADLs, they may be more accustomed to the role and had enough time to re-arrange the other parts of their lives.

Caregiver Stress

Caring for PWD can be extremely demanding on family caregivers as the disease progresses. This is mainly due to few family caregivers not receiving formal training in skills needed to provide appropriate care (DiZazzo-Miller, Samuel, Barnas, & Welker,

2014). Due to this lack of formal training, family caregivers experience stress when caring for PWD.

Caregiver stress can be defined as the actual or perceived physical or emotional strain experienced by the caregiver as a result of caregiving activities. Caregiver stress increases when a PWD exhibits challenging behaviors that manifest as part of the disease. These behaviors include: agitation, wandering, resisting care, destructive behaviors, physical and verbal aggression, hoarding or distressful feelings. Evidence suggests that family or informal caregivers find these behaviors difficult to manage (Piersol et al., 2012).

When family members take on the role of caregiver, it can be associated with physical and emotional stress (Liew et al., 2010). Psychological health problems such as depression, impaired immune response, stress, sleep deprivation, anxiety, family discord and social isolation are associated with negative outcomes of caregiving (Narayan, Lewis, Tornatore, Hepburn, & Corcoran-Perry, 2001). Family caregivers' lives are often filled with other roles. These roles include but are not limited to worker, spouse, parent, volunteer, and the new role of caregiver, which may be viewed as out of place in the life cycle. Family caregivers can also experience barriers to social support or service availability, accessibility, or acceptability that could help them adapt to caregiving demands. Moreover, the context of care typically spans a combination of these and other barriers; as a result, family caregivers may feel a sense of helplessness, believing that they do not have what it takes to meet the next caregiving challenge (Coon, 2012).

Caregiving as a Positive Experience

Positive aspects of caregiving have been identified in a variety of ways. These positive aspects are typically defined as the rewards and satisfaction derived from the caregiving relationship (Hilgeman, Allen, DeCoster, & Burgio, 2007). Satisfaction with caregiving and rewarding appraisals of caregiving may reduce caregiving stress and improve emotional outcomes (Hilgeman et al., 2007). A range of positive experiences as a caregiver has been identified including a sense of fulfillment, importance and responsibility, and finding companionship and meaning within the relationship (Hilgeman et al., 2007) The revised Stress and Coping Model explains that positive psychological appraisals and burdens can be experienced simultaneously when caregivers go through challenges (Liew et al., 2010). Personal growth and gains in relationships and spiritual growth are some of the positive caregiving outcomes mentioned in the literature (Liew et al., 2010). Factors that have shown to facilitate the experience of gains include: having a good relationship with a PWD; being a caregiver by one's own initiative; coping with less venting emotions; and being able to maintain leisure time despite the ardors of caregiving (Liew et al., 2010). Caregiving provides adult children an opportunity to repay a parent for many years of care and to experience personal gratification for doing a job well (Hogsel, Curry, & Walker, 2005-2006). Family members who have been caregivers in the past can derive satisfaction by helping other caregivers. Sometimes just being with an older person can be rewarding (Hogsel et al., 2005-2006).

Evidence-Based Interventions: Non-Occupational Therapy and Occupational Therapy

Non-Occupational Therapy Interventions

Providing effective interventions to reduce caregiver burden is an important aspect in providing quality of care to caregiver dyad members (Etters, Goodall, & Harrison, 2008). Caregiving counseling and support groups that include the caregiver and other family members have been shown to have positive effects on caregiver depression and reaction to problematic behavior (Thinnes & Padilla, 2011). Adult day care facilities are somewhat helpful in alleviating care-related stress by enhancing caregivers' opportunity to take part in social activities and provide respite care (Thinnes & Padilla, 2011).

Successful techniques when caring for a PWD may be counterintuitive to caregivers (Piersol et al., 2012). Their best intentions may trigger certain types of behaviors. For example, not correcting a mistake or going along with something that is not true may feel deceitful and wrong to the family member providing care; however, this strategy may minimize problematic behaviors of people with dementia. Research shows that family caregivers benefit from training in managing behaviors and promoting function in a PWD (Piersol et al., 2012).

Occupational Therapy Interventions

Occupational therapists are educated about the consequences of dementia and trained in the cognitive and behavioral treatment that sustain and improve autonomy, social participation, quality of life, and health status (Graff et al., 2007). They play a

fundamental role in developing strategies for helping families effectively cope with dementia.

Occupational therapy interventions utilizing daily occupations facilitate successful occupational engagement to help foster the relationship between the caregiver and care recipient. Successful occupational engagement has been identified by caregivers as a way of evaluating and monitoring well-being. Occupational engagement is also an important source of satisfaction that indicate if caregivers are providing good care (Williams, 2016).

Occupational therapists have developed interventions contributing to the facilitation of successful occupational engagement in the caregiving situation. Certain interventions include: training in time management skills; distributing care responsibilities; training in behavior management; emphasizing caregivers' continuing leisure activities; utilizing community resources; and using relaxation and stress management techniques (Williams, 2016).

As part of a broad range of behavioral and environmental intervention strategies, training caregivers in specific communication skills has been identified as an important approach, and one that occupational therapists are particularly qualified to address. They are trained to help families by providing optimal communication with PWD. They do this by: evaluating the clients' abilities; setting goals; identifying barriers and motivating factors collaboratively with caregivers and team members; educating families about the disease process; providing opportunities to use adaptive communication strategies

during daily routines; and supporting retained capabilities of persons with dementia (McKay & Hanzaker, 2013).

In regards to developing individualized and timely interventions for caregivers and care recipients, occupational therapists must have the ability to effectively read and understand the context of the caregiver situation. Practitioners should establish collaborative reasoning with the caregiver to accurately frame problems within the caregiving context which includes viewing the caregiver as the expert. Learning caregiving skills under the guidance of experienced professionals such as occupational therapists will help improve the quality of care. Interventions customized to the individual caregiver were found to support health behaviors and reduce health disparities and lead to successful outcomes (Williams, 2016).

Concluding Thoughts

Dementia is a progressive disease that will continue to affect the older population in years to come. As the disease progresses, the person with dementia requires consistent supervision by a caregiver. Caregivers will experience some positive experiences; but most of the time there are negative outcomes associated with caring for PWD such as stress, depression, and burden of care. This literature review on occupational therapy interventions has emphasized the importance of occupations, its relation to occupational engagement, and successful interventions. But what is needed now is a synthesis of interventions which occupational therapists can use. The intent of this research study was to develop such a protocol of interventions that will lead to better quality of care for care recipients and better health outcomes for caregivers.

CHAPTER III

CAREGIVER PERSPECTIVES: A MIXED METHODS STUDY

Family caregivers are any relative, partner, friend, or neighbor who provides a broad range of assistance to adults with disabling conditions such as dementia. Family caregivers must be willing and able to handle potentially complex health, financial, legal, and social needs over a period of months or years. Evidence show that caregivers who are involved in the care of a PWD contributes to greater care receiver satisfaction and improves continuity of care. However, evidence also indicates that caregivers do not receive adequate recognition or support from health care professionals. Most payers and providers do not acknowledge that family caregivers are an extension of the care delivery team and may need care themselves. Research shows there are a number of suggested reasons why caregivers are not more integrated into the health care delivery system (O’Sullivan 2015). Such reasons include:

- Medical insurance providers focus on the patient or client, rather than the family member providing care.
- Health care providers say they do not have time to talk or train family caregivers. The possible reason behind this is that health care providers are not paid to do so.
- Providers and family caregivers lack adequate communication skills.
- Privacy rules under the Health Insurance Portability and Accountability Act (HIPAA) have been misinterpreted and misapplied by health care providers, leaving families without access to information.

- Health care providers may perceive families as intrusive and time consuming.

This first study will explore family caregivers' perspectives and experiences with caring for a family member with dementia/Alzheimer's and the need for specific interventions that lessen the burden of care and improve satisfaction with caregiving.

Research Design

This research study used a mixed method design combining quantitative and qualitative methods. A mixed method design is a method for collecting, analyzing, and combining qualitative and quantitative methods in a single study to understand a research problem (Nova Southeastern University, n.d.). The quantitative method portion consisted of administering the Picot Caregiver Reward Scale (PCRS) (Picot, Youngblut, & Zeller, 1997) which assesses rewards of caregiving. The qualitative method portion consisted of a focus group. A focus group is a group discussion conducted by an investigator who guides the discussion by introducing questions, usually from a written set of topics (Patton, 2002). There are several benefits of a focus group. These benefits include: allows the investigator to interact with the participants and pose follow up questions to get more in depth with conversation; the investigator can retrieve information from non-verbal responses such as facial expressions and body language; results are more understandable; and the information that is obtained is gathered more quickly than individual interviews (Copley Focus Centers, 2017).

Participants

Caregivers who qualified for the study cared for a family member with dementia for a minimum of three months and who now was living in a long-term care facility, were at least 50 years of age, and related to the caregiver either through blood or marriage. Criteria for the family member with dementia required that the person needed assistance with one or more Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) and was living in a long-term care facility.

Data Collection Tools

The quantitative method consisted of administering the PCRS via phone to each caregiver. The PCRS assesses rewards of caregiving, and the items are based on rewards that demonstrate personal growth of the caregiver as well as growth in the relationships between caregiver and care receiver, family, friends, and health care professionals (Picot et al., 1997). The caregivers rated the degree to which items describe positive experiences of their caregiving on a 5-point Likert scale ranging from “not at all” to “a great deal.” (Picot et al., 1997). The tool has alpha coefficients of .83 and .88. See Appendix A for the PCRS.

The qualitative method involved a focus group comprised of those same five caregivers who completed the PCRS via phone. The focus group was also guided by an interview guide. The investigator provided verbal probes or cues to encourage the caregivers to provide as much detail during the focus group interview. The focus group interview was audiotaped then transcribed. See Appendix B for focus group interview guide.

Data Collection Procedures

The investigator met with the Early-Stage Programs Manager from the local Alzheimer's Association several times via phone, email, and face to face. The discussions were regarding detailed information about the research study and type of participants needed. The Early-Stage Program Manager explained that the participants were involved in support groups affiliated with the local Alzheimer's Association and all had family members in long term care facilities. The Early-Stage Program Manager explained that she would speak with the participants she had in mind to see if they would be interested in participating in the research study. If the participants were agreeable, the Early-Stage Program Manger would provide the investigator with each participant's name and email addresses. Over the course of two weeks, the Early-Stage Program Manager was able to provide contact information of five caregivers who were interested in participating in the research study. Once the contact information was retrieved, all five caregivers were emailed regarding detailed information of the research study. The information provided to the caregivers were: name of the study, purpose of the study, and caregiver's role in the study. Each participant was efficient with responding to the email and confirmed that they would be willing to participate. Each caregiver provided the investigator with their contact number to provide consent by phone and perform the PCRS. Caregivers were asked via email about their availability for a phone interview. Four out of the five caregivers were able to provide their availability via email. The fifth caregiver provided his availability via phone. Each caregiver was individually interviewed. Most interviews were performed on a Saturday

morning prior to the caregiver visiting his or her family member in the long term care facility. Each phone interview started off with each caregiver providing verbal consent and agreeing to signing consent forms at the focus group. Prior to administering the PCRS, each caregiver was asked to share information about their family member with dementia and the reasons he or she chose to participate in this study. During this process it was found that all the caregivers had a wife or husband with Alzheimer's. The main information provided about each caregiver were: the care receivers' ages, how long they have been married, signs of dementia, formal diagnosis date, and long term care placement. The PCRS was administered to each caregiver. Some caregivers required extra time to think about each question prior to answering or required detailed explanation or repetition of certain questions. The phone interviews lasted between 20 – 30 minutes.

After each individual phone interview was conducted, the investigator emailed each caregiver their completed PCRS. During each email, the caregivers were asked their availability for a focus group. The investigator used Doodle to help find a suitable date for a meeting with this group. Once the Doodle calendar was completed, it was provided to each caregiver. Each caregiver chose a date on the calendar provided with everyone agreeing to a Sunday evening focus group. Prior to the focus group, the caregivers were provided with information via email. The information that was stated in the email included: please bring completed PCRS to meeting to discuss in more detail, signed consent forms, meeting time, and location. Each caregiver provided a confirmation email stating they would be able to meet at that specific location and bring

all information. The focus group was held at one of the caregiver's home. During the focus group, it was found that each caregiver was Caucasian and between 60-74 years of age. Prior to the focus group, each caregiver was provided with code names for confidentiality purposes: Caregiver 1 (CG 1), Caregiver 2 (CG 2), Caregiver 3 (CG 3), Caregiver 4 (CG 4), and Caregiver 5 (CG 5). Before beginning the focus group, the investigator obtained the signed consent forms for the caregivers' participation in the research study and explained the purpose of the research study and what the focus group would entail. The focus group consisted of each caregiver providing detail information on PCRS; providing the number they rated each question and to elaborate on the reasons they chose that specific number. The investigator also used an interview guide to help assist with elaboration or provision of more information. The focus group was audiotaped and lasted for 2 hours and 2 minutes. The purpose of the focus group interview was to identify and examine key points that could be of help to other caregivers who are experiencing burden of care from caring for a person with dementia and/or benefits of caregiving.

Data Analysis and Results

Focus Group

After completing the transcription of the focus group, the investigator was able to develop three tables: Demographic Table for Caregivers, Demographic Table for Care Receivers, and Trajectory of the Disease for CRs. The Demographic Table for Caregivers included: Participants, Relationship, Years Married, Age, Ethnicity, and Educational Background. The Demographic Table for Care Receivers included: Care Receiver (CR),

Diagnosis Date, Age Diagnosed/Current Age, and First Signs of Dementia. The Trajectory of the Disease for CRs discusses each CRs' signs, symptoms, and progression of Alzheimer's disease. See Tables 1, 2, and 3.

Table 1

Demographic Table for Caregivers (CG)

Participants	Relationship	Years Married	Age	Ethnicity	Educational Background
CG1	Husband/Wife	41 years	CG1: 63 y/o	Caucasian	College Level/Board Chairman
CG2	Husband/Wife	33 years	CG2: 60 y/o	Caucasian	College Level/Proposal Manager
CG3	Husband/Wife	51 years	CG3: 75 y/o	Caucasian	College Level Education
CG4	Wife/Husband	45 years	CG4: 66 y/o	Caucasian	College Level/Journalism
CG5	Husband/Wife	50 years	CG5: 74 y/o	Caucasian	College Level/Retired Chemical Engineer

Table 2

Demographic Table for Care Receivers (CR)

Care Receiver	Date Diagnosed	Age Diagnosed/Current Age	First Signs
CR1	May 2011	57 y/o/62 y/o	-Not remembering things/STM deficits -Moody -Grumpier than normal
CR2	May 2005	55 y/o/66/y/o	-Words would be misspelled, trouble with math. Words being un-spelled for her was unusual because she was an English major so spelling was a big thing for her.
CR3	January 2012 or 2013	67 y/o/71 y/o	The grandchildren noticed that she was asking the same questions; took her to the airport and called 3 times to find out where the exit was/STM deficits.
CR4	March 2006	63 y/o/74 y/o	-Forgetting things -problems using cell phone -Driving wasn't as good (always been a good driver) -misplaced things -very slow with a lot of things
CR5	August 2011	66 y/o/71 y/o	- Kids noticed they're mom had a hard time coming up with right word or aphasia.

Table 3

Trajectory of the Disease for CRs

Care Receiver	Trajectory of the Disease
CR1	<ul style="list-style-type: none"> - Short Term Memory (STM): Ex: difficulty using cell-phone or forgetting to meet CG1 for lunch at their favorite restaurant. - Verbal and physical agitation. - Sleeping until noon (not typical) - Daughter noticed something wrong with CR1. Requested for CG1 to do something. - 2009: Misdiagnosed: Diagnosed as depression. - 2011-2015: CG1 took care of CR1. - 2015: UTI which affected cognition more. Placed in Country Village of Angleton. Once UTI was resolved, transferred back home. Hired assistance. Required Tot A with basic activities of daily living (BADLs). - Placed in facility due to Tot A with BADLs and aggressive/combatative behavior.
CR2	<ul style="list-style-type: none"> - 2004: struggled with STM (asked CG2 same questions over and over again). - Difficulty with math and misspelling words (not typical due to CR2 being an English major). - 2005: Received formal diagnosis of Alzheimer's. Once diagnosed became more thoughtful. - Started experiencing difficulty with dressing and bathing. - Ability to verbalize went away - CG2 cared for CR2 for 8-9 years. - 2012: Placed in Sheltering Arms for a few years. 2014: Placed in Village of Meyerland due to continued progression of disease. 2016: Hospice: came down with pneumonia and pressure sore. Sept. 2016: Passed away.
CR3	<ul style="list-style-type: none"> - STM deficits (asking same questions). - Required complete assistance with bathing due to forgetting how to bathe. - Wandering; trying to escape. - CG3 cared for CR3 for 3.5 years. - Placed in Sheltering Arms. - While at Sheltering Arms exhibiting inappropriate behavior such as kissing other females.

	<ul style="list-style-type: none"> - CG3 requested for a medication change by psychiatrist to stop inappropriate behavior. - Placed in Autumn Leaves. - Exhibits decrease memory and incontinence.
CR4	<ul style="list-style-type: none"> - STM deficits - Problems with using cell phone. - Ability to drive declined. - Very slow processing skills. - Misplaced things. - Wandering - Getting lost while driving. - Repeating himself. - Dependency with self-care activities. - Formally diagnosed with Alzheimer's in 2006. - CG4 cared for CR4 for 8 years. - Placed in long term care facility due to increase dependency.
CR5	<ul style="list-style-type: none"> - Aphasia which progressed. - Paranoia - August 2011: Formally diagnosed with Alzheimer's. - Nov. 2015: physical aggression (kicking). - Dependency with BADLs - Needed help with changing tv/needed help with everything. - Evaluated by geriatric psychologist and recommended placement. - Placed in Light Heart Facility.

While creating the tables, it was found that each couple had been married for 33 years or more. The care receivers were between the ages of 62-74 years of age and all were Caucasian. The care receivers were also diagnosed between 55-67 years of age and all were identified as having Early-Onset Alzheimer's. As the investigator continued with the development of the demographic table, it was found that the majority of the CRs experienced early signs of Alzheimer's. One of the most common early signs noted was short term memory deficits. The caregivers were able to provide specific examples of short term memory deficits, for example: CG1 reported that CR1 had an experience with forgetting to meet CG1 at a specific restaurant for lunch. CG1 shared this story:

Once a week we would go to lunch together. I would go to the restaurant we said we would meet, but she wasn't there. I would call her, but she wouldn't answer her phone. When I would go home, she was at home. When I would tell her that we were going to meet at that specific restaurant, she would go to pieces. She didn't remember.

CG3 reported that a specific sign of short term memory deficits with CR3 was when CR3 was driving to the airport and called CG3 three times to ask about a particular exit that would lead to the airport. Some other early first signs shared by the caregivers included: moodiness; grumpiness; misspelled words; trouble with math; difficulty with using cell phone; difficulty driving; and aphasia.

The investigator created a Table that looked at the Trajectory of the Disease for each CR. Patterns included: the majority of the care receivers started with short term memory deficits; then progressed to combative behaviors and verbal agitation; lastly, requiring complete assistance with ADLs such as toileting and bathing.

Below are two tables that illustrate the challenges and positive aspects with caregiving. These tables were derived from patterns that came directly from the CG quotes. Please see Tables 4 and 5.

Table 4

Challenges with Caregiving

Common Signs that caused concerns for CGs	Difficulty with BADLs	Negative Changes with Alzheimer's	Challenges with Caregiving	Behaviors that trigger placement in LTC facilities
<p>-Short term memory deficits: "Calling several times to ask same questions; forgetting how to use a phone/calling someone was difficult." -Grumpy -Moody -Forgetting math problems. -Difficulty spelling words</p>	<p>-Care Receivers requiring more assistance with self-care ADLs particularly with bathing requiring a second person to assist to lessen burden. - Problems with sequencing bathing task. -Safety concerns with bathing: Falling.</p>	<p>-Verbal aggression -Physical aggression/combativeness -Paranoia -Constantly needing the caregiver's time. -Difficulty verbalizing needs/aphasia.</p>	<p>-Trying to do care for your loved one alone. "Realizing that whatever you loved one is doing such as hurting you or saying mean things, that is not the person you married. It's the disease." "Doesn't matter who is watching your loved one, something can still happen: wandering off." -Trying to escape. "Finding a hospital or clinic that will provide help and guidance when trying to figure out what is wrong with your loved one." - "Not enough family friendly bathrooms/too many stalls in bathrooms." -Making the decision to place your loved one in a facility.</p>	<p>- Verbal aggression - Physical aggression/combativeness - Dependency with self-care ADLs: Participants mainly expressed concerns with bathing and toileting: fear of falling/breaking a bone, forgetting how to bathe/difficulty sequencing steps; 2-person assist with toileting/perineal hygiene (required a second person to assist with these needs) -Well-being: Participant want to prevent from getting sick and/or dying. Participant shared that they have had friends who have done this and died before the person they were caring for. Being able to take of</p>

			<p>“Making the decision alone. Family does not want to get together to help make the decision.” (mainly extended family)</p>	<p>yourself/exercising (walking). -Trying to leave home -Getting lost -Paranoia/thinking someone was taking items from home, didn't want anyone in the home. -Limited in-home assistance/unreliable caregivers: lacked consistency; at times the person didn't show up to care for the care receiver</p>
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Table 5

Positive Aspects of Caregiving

Positive Changes with Alzheimer's	Benefits of Caregiving
<ul style="list-style-type: none"> - “Can bring couples closer for a few years/more intimate talks.” - “Relationship can be much deeper: as you live your life, things interfere in your relationship (work, kids, etc.). Sometimes you feel like you grow apart. But now you see what's left of your partner: essence and soul. Seems like it's more than ever.” - More affectionate - “Holding hands, going for walks. It's not a complex relationship like we were younger.” 	<ul style="list-style-type: none"> - “Learning more about Alzheimer's, dementia, and/or disability has made caregivers more understanding and accepting of people.” - “Able to help people who are experiencing the same thing.” - “Allowed caregivers to become a better person around people but also helping others by facilitating support groups; working with Alzheimer's patients; helping at Alzheimer's seminars; and helping to raise money for Alzheimer's.” - “Trying to come together to form more resources to help caregivers.” - You meet many new friends who are going through the same thing as you especially if you are part of a support group. It helps to

	<p>know that you're not alone. It allows us to all learn together and make new connections.”</p> <ul style="list-style-type: none"> - “Feelings of accomplishment.” - “Strength: You don't know how strong you are until you face it.” - “Knowing your capability...strength, love, and commitment.”
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In summary, the qualitative information obtained was converted into tables that were derived from the caregiver interviews, PCRS, and interview guide questions. Based upon the CG quotes, the investigator was able to dissect the information and describe the challenges associated with caregiving, but most importantly, identify the positive aspects. These data, in turn, were essential as the protocol manual was developed.

PCRS

The scoring of the PCRS consisted of the summation of scores with higher scores indicating higher perceived rewards (Picot et al., 1997). The PCRS was scored for each caregiver. Please see table of scores below.

Table 6

CG PCRS Scores

CGs	Summation of scores on PCRS	Average Score on PCRS
CG1	69	3
CG2	60	3
CG3	62	3
CG4	61	3
CG5	67	3

Note. An average score of “3” indicates “Quite a lot” which describes how positive their experiences have been with caregiving.

There were several questions the caregivers scored a “4” or “a great deal.”

The questions that each caregiver scored a “4” were:

- “I feel I have become a stronger, tolerant, and/or patient person around persons with sickness or disabilities.”
- “I feel nurses, doctors, and social workers work harder to care for my friend/relative too.”
- “Receiving a smile, touch, or eye contact from my friend/relative is important.”
- “I feel I have become a better person by learning new information.”
- “I feel that I have made many new friends.”
- “I feel I have freedom to make decisions that matter.”

The caregivers were able to provide detailed reasons for scoring these particular questions a “4.” Specific responses provided were:

- “These people are amazing (doctors, nurses, and social workers). It’s their calling.”
- “It makes us smile when we receive a smile, touch, or eye contact.”
- “I knew next to nothing about Alzheimer’s and mental health diseases. Learning about Alzheimer’s, dementia and disability has made me much more understanding and accepting of people.”
- “I’ve become a better person around all people. This has allowed me to facilitate support groups, work with Alzheimer’s patients, Alzheimer’s seminars, and raise money. All sorts of things have come out of this.”
- “Made many new friends. Unfortunately, we are in the same sad show.”

- “Learning together and making new connections at the Alzheimer’s center.”
- “I feel more important because I’m making a lot of decisions for my wife. I’m taking care of everything. All the bills; everything.”

During the focus group interview several interview guide questions were used. One question that was used was: “What are some challenges with caring for a family member with dementia/Alzheimer’s?” The main response from all caregivers was:

- “Get help because you can’t do this by yourself. If you try to do this by yourself, you will go down.”
- “You feel isolated if you don’t get help.”

Another interview guide question was: “Do you feel when someone is helping you, does it lessen the burden of care?” Everyone agreed to “yes.” All CGs provided an explanation to this question. See below their responses:

- CG 1 explains that the assistance allowed time to do groceries and exercise.
- CG 4 explains that help is good but also realizing that managing the help will be a full time job. CG 4 went on to explain: “That was one of the reasons why I placed my husband in a facility because I was unable to find a reliable caregiver. They either lacked consistency such as not showing up to care for him.”

The last interview guide question that was asked to the caregivers was, “What are some benefits/rewards for caring for a family member with dementia/Alzheimer’s?” The CGs provided various responses. See below:

- CG 3: “Feeling of accomplishment.”
- CG 2: “You don’t know how strong you can be until you face it.”

- CG 4: “Knowing your capability: strength, love, and commitment. You come to realize you’re not just capable of these things, you do them.

Discussion

Findings showed that the care receivers’ common first signs were short term memory deficits and then progressing to complete dependence with basic activities of daily living. The triggers for placement ranged from verbal and physical aggression to complete dependence with basic activities of daily living, specifically with bathing and perineal hygiene. Caregivers also shared information regarding Negative Changes with Alzheimer’s; Positive Changes with Alzheimer’s; and Challenges with Caregiving. Based upon the data that were transcribed from the caregiver focus group and occupational therapists’ interviews, which will be discussed in Chapter 4, a proposed caregiver intervention protocol manual was developed to assist occupational therapists with strategies that would enhance a positive relationship between caregiving dyad members.

Limitations

There were several limitations to this study. Limitations include a small sample of caregivers and conducting one focus group. This limited the amount of information that could be obtained and implemented into the intervention protocol. The minimum amount of information may not have allowed for a more detailed intervention protocol. Another limitation was lack of detailed responses from the caregivers regarding the rewards and benefits of caregiving. The investigator should have used more probing questions to help the caregivers provide details to the answers that were provided on the PCRS and interview guide questions.

Conclusion

In conclusion, the trustworthiness or creditability of this study was based on member checks or providing the participants with the results of the data so they can verify accuracy (Pitney, 2004). The data that were transcribed were converted to a table based on the caregiver's quotes or answers provided during the focus group interview. The information was divided into several categories: Common Signs that caused concerns for CGs; Difficulty with BADLs; Negative Changes with Alzheimer's; Challenges with Caregiving; Behaviors that trigger placement in LTC Facilities; Benefits of Caregiving; and Positive Changes with Alzheimer's. The information provided under the categories discussed will be used when creating interventions for the caregiver intervention protocol manual.

CHAPTER IV

A VIEW OF FAMILY CAREGIVING EXPERIENCES FROM THE PERSPECTIVES OF OCCUPATIONAL THERAPY PRACTITIONERS

This study was developed based on the need for occupational therapists' input or perspectives on ways to lessen caregiver burden. By lessening the burden of care, occupational therapists can help facilitate positive dimensions of care through the use of specific interventions that have been successful while working with persons with dementia (PWD) and their caregivers.

Research Design

The purpose of the second study examined ways in which occupational therapy currently facilitates positive dimensions of care. This study was a phenomenological study design. A phenomenological study design seeks to understand the significance, structure, and essences of the lived experience of a phenomenon for one or more people (Patton, 2002). Individual interviews were conducted with occupational therapists to obtain their perspectives on the experiences of working with caregiving dyad members.

Participants

The participants for this study consisted of four occupational therapists who are currently working or worked in inpatient rehab facilities, home health agencies, skilled nursing facilities, acute care settings, or memory homes in the metropolitan area and whom the investigator personally knows. The occupational therapists were at least 24

years of age and had a minimum of two years of experience including work with PWD and their caregivers.

Data Collection Tools

A formal letter was sent to the four occupational therapists via email. The letter included the study's name, purpose of the research study, occupational therapists' role regarding the study, and the investigator's contact information if they had questions. An informed consent for their participation in the research study was sent via email and signed prior to participation in the study. An interview guide was also sent via email for the occupational therapists to answer. The interview guide included questions pertaining to years of experience; experiences while working with PWD; interventions that have been successful when working with PWD; experiences with dementia caregivers; interventions and education provided to caregivers to help limit the amount of stress with caregiving; and interventions and education provided to caregivers to help maintain positive relationships between themselves and their family member with dementia. See Appendix C for the occupational practitioner interview guide.

Data Collection Procedures

All four occupational therapists who agreed to participate in the study are currently working, so for the sake of time, they were provided with the formal letter, consent form, and interview guide via email. Prior to sending the interview guide, the investigator did provide information via email regarding detailed information about the research study and the occupational therapist's role in the research study. Once that information was provided, the occupational therapists were sent the interview guide. The

occupational therapists were able to contact the investigator via email or phone if they had any questions or concerns.

Data Analysis and Results

The investigator began analysis by reading through the information provided by the occupational therapists to find similar responses and/or themes to help create content for the caregiving intervention protocol manual. While reviewing the information, the investigator developed two tables: Table 7. Demographic Table for Occupational Therapists and Table 8. Table of Occupational Therapy Interventions. The tables were organized to identify and describe common patterns among the therapists' responses. The tables consisted of the participants' code names; years of experience; age; gender; successful interventions that the occupational therapists provided to PWD; interventions or education used to alleviate caregiver stress when caring for a family member with dementia; and interventions or education that helped provide positive relationships between caregiving dyad members. Please see Tables 7 and 8.

Table 7

Demographic Table for Occupational Therapists

Participants	Years of Experience	Gender	Age
OT1	38 years	Female	61
OT2	34 years	Female	58
OT3	12 years	Female	39
OT4	9.5 years	Female	37

Table 8

Table of Occupational Therapy Interventions

Successful Intervention for Dementia Patients	Interventions or Education used to Limit Caregiver Stress	Interventions or Education that provided Positive Relationships between Caregiving Dyad Members
<ul style="list-style-type: none"> -Interventions to no >1-2 different training and/or education intervention during 1 treatment session (many times 1 is maximum that patient can handle) -Decrease external stimuli/distractions during treatment session to improve ability to attend to tasks -Provide only simple 1-2 step instructions to increase ability to follow and carryover verbal instructions -Provide visual demonstrative cues to increase comprehension of instructions. -Provide repetitive opportunities to demonstrate tasks for comprehension and carryover. -Structure patient's room and environment to increase orientation to person, place, time, and situation and for safety (remove barriers like too much furniture, rugs; place 	<ul style="list-style-type: none"> -Structure self-care tasks to include performing the same tasks (brushing teeth, bath dressing eating) at the same time daily. -Set up self-care tasks for patients (as appropriate to patient's cognitive needs) in the same place daily before self-care tasks are performed to improve independence and decrease distraction. -Provide meals and medications at the same time daily. -Allow patient to make simple safe decisions (tv shows, place to sit, choice of foods) to give sense of independence -Provide patient with activities they enjoy during free time (puzzles, game shows) -Provide patient with increased PRAISE for tasks completed to give a sense of worthiness and independence 	<ul style="list-style-type: none"> -Allow others to help you by telling them specifically what you need (i.e. specific days and times to run errands, perform hobby, relax away or at home; overnight or weekend care to give you a break and much needed rest; financial needs for medications, etc.) -Seek out community and financial resources (i.e. specialized adult day care centers, respite care, Veterans Aid and Dependent Benefits, etc. - "I believe that family education is extremely important when dealing with dementia patients." - "It is also important for family members to be aware of the kind of assist that is available outside of the hospital setting. By utilizing programs such as Meals on Wheels, Via Trans and adult day care can often make living with dementia patients more comfortable and manageable."

<p>simple large letter calendars and cross of dates daily with patient or large digital clocks that have day of week, date, time; pictures of closest family members or friends).</p> <ul style="list-style-type: none"> -Simple tasks (grooming, crafts- they loved to do) -Looking at photos of their past. -If they enjoyed gardening, included in treatment sessions. -Music -Pictures of patient's family and loved ones. -Therapeutic use of self, adjusting my conversation and interaction according to the patient's reality at that time as long as it was safe and appropriate. -Decorations to a time or era that has made the patient happy or engaged. -Complete therapy sessions outside. - Establish a daily routine early. -Maintain same schedule daily. -Encourage patients to fully participate in all ADLs. -Family training to help family slowly transition to new role. 	<ul style="list-style-type: none"> -Allow others to help you to care for your loved one. - "I have educated caregivers to contact family or friends to assist with sitting with their love one while they get out to run errands, go to the movies. Get involve with support groups and/or church." -Educate caregiver to develop a daily schedule so their love one will be on a regular daily routine as much as possible. -Educate family and caregivers about the different stages of dementia and what to expect in each stages. Train and educate the family member on support groups/resources available in the area. - "Sometimes I just let the family/caregiver just talk." -Educate family members that no one person can care for patient that requires 24-hour supervision. "We often encourage family members to stay with patient overnight, so they will know what to expect when the patient goes home. Caregivers often complain of sleep deprivation after the 	
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	<p>overnight stays. They usually state that they are not able to sleep because they worry about their loved one getting up in the middle of the night. Therefore, the importance of getting family and friends involved is necessary and important to establish early to prevent ‘burn-out.’”</p> <p>-Encourage family members to continue with any hobbies or other leisure activities they enjoy doing to help relieve stress for caregiver and loved one.</p>	
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Results

After completing the Demographic Table and Table of Interventions, the investigator reviewed the data to find common patterns. Below are lists of common patterns that were found.

Successful Interventions for PWD:

1. Structuring patients’ environment to increase orientation to person, place, time, and situation and for safety.
2. Pictures of closest family members or friends.
3. Allowing patients to participate in simple tasks (grooming, crafts they love to do).
4. Looking at photos of their past.
5. Allowing patients to participate in activities they enjoy such as gardening.

6. Provide pictures of patient's family and loved ones.
7. Establishing a daily routine early; maintaining same schedule daily.
8. Encourage patient to fully participate in all ADLs.
9. Family training to help slowly transition family to new role.

Experiences with Informal Caregivers of Persons with Dementia:

1. Providing resources for specialized Alzheimer's and dementia day care, respite care and support groups.
2. Providing methods re: structuring ADL/self-care, home environment, and medication management.
3. Providing education on how to involve their loved ones with personal hygiene, simple household chores (folding clothes, washing dishes, helping with putting groceries up after shopping).

Interventions and/or Education Used to Manage Caregiver Stress:

1. Structuring self-care tasks to include performing the same tasks at the same time daily (brushing teeth, bathing, dressing, eating).
2. Set up self-care tasks for patients (as appropriate to patients' cognitive needs) in the same place daily before self-care tasks are performed to improve independence and decrease distraction. Provide meals and medications at the same time daily.
3. Educate caregivers to contact family members or friends to assist with sitting with their loved one while they run errands.
4. Get involve with support groups.

5. Educate caregiver to develop a daily schedule so their loved one will be on a regular daily routine as much as possible.
6. Train and educate families on support groups or resources that are available in their area.
7. Educate family members that no one person can care for a patient that requires 24-hour supervision.
8. Educating family that it is important to get other family members and friends involved to prevent “burn-out.”
9. Encouraging family members to continue with any hobbies or other leisure activities they enjoy doing to help relieve stress for caregiver and loved one.

Interventions and/or Education that Facilitated Positive Relationships between Caregiving Dyad Members:

1. Allow others to help you by telling them specifically what you need (i.e. specific days and times to run errands, perform hobbies, relax away or at home; overnight or weekend care to give you a break and much needed rest; financial needs for medications, etc.).
2. Seek out community and financial resources (i.e. specialized adult day care centers, respite care, Veterans Aid and Dependent Benefits, etc.).
3. Educate families on the kinds of assistance that is available outside of the hospital setting. Utilizing programs such as Meals on Wheels, Via Trans, and adult day care can make living with persons with dementia more manageable and positive.

After completing the above data analysis, the investigator was able to review and find repeated patterns and synthesize them into the following intervention approaches according to the PEO model.

Person Strategies

1. Provide photos of the patient's past and/or family members and loved ones.
2. Allowing patients with dementia to participate in simple ADL tasks and activities they enjoy doing. Provide meals and medications at the same time daily.

Environment Strategies

1. Provide a structured environment such as establishing a daily routine: performing the same tasks at the same time daily. Set up self-care tasks for the (as appropriate to person's cognitive needs) in the same place daily before self-care tasks are performed to improve independence and decrease distraction.
2. Provide meals and medications at the same time daily.

Occupations

1. Allow PWD to participate in simple ADLs and IADL tasks such as grooming, folding clothes, washing dishes, helping with putting groceries up after shopping.
2. Allow patient to participate in activities they enjoy doing/leisure activities such as crafts, gardening.

Resource strategies for Family Caregivers

1. Family training: provide education on how to involve their loved ones with personal hygiene, simple household chores such as folding clothes, washing dishes, or helping with putting groceries away after shopping.

2. Seek out community and financial resources such as specialized Alzheimer's adult day care centers, Respite Care, Veterans Aid, Meals on Wheels, Via Trans, and Dependent Benefits).
3. Educate family on the importance of allowing other family members and friends to assist with their loved one to prevent burn-out. Allow others to help by telling them specifically what you need (i.e. specific days and times to run errands, perform hobbies, relax away or at home; overnight or weekend care to give you a break and much needed rest; financial needs for medications, etc.).

Discussion

Findings show that after careful analysis of the data derived from the study, the investigator was able to find appropriate content for the intervention protocol. The investigator was able to review the demographic tables and find common patterns. All patterns were placed in specific categories. These categories were: successful interventions for persons with dementia; experiences with informal caregivers of persons with dementia; interventions and/or education used to manage caregiver stress; and interventions and/or education that facilitated positive relationships between caregiver dyad members. After finding common categories, the investigator was able to find repeated themes and synthesize them into the following intervention categories: person strategies; environmental strategies; occupations; and resources strategies for family caregivers. This information was used to form a caregiver intervention protocol. Please see Appendix E for completed caregiver intervention protocol manual.

Limitations

This study had limitations. One limitation is the small sample of therapists which limits the amount of rich information that can be retrieved compared to recruiting a larger sample. Another limitation is providing data collection tools via email. If the interviews were administered through phone or face to face, more detail or specific information might possibly have been retrieved from the participants. This could have been done by using additional questions such as: “Can you be more specific or expand on the answer you provided?” or “Can you provide detail examples?”

Conclusion

In conclusion, the trustworthiness or creditability of this study was based on member checks or providing the participants with the results of the data so they can verify accuracy (Pitney, 2004). The data that emerged from the therapists’ interviews provided rich and informed information that was then utilized in the caregiver intervention protocol manual. From even this small sample of therapists, a wealth of valuable intervention approaches was identified.

CHAPTER V

DEVELOPMENT OF A CAREGIVER INTERVENTION PROTOCOL AND PROGRAM EVALUATION

Based upon caregivers' responses from the PCRS, a focus group of caregivers, interviews with occupational therapists, and a thorough review of current best evidence, the investigator developed synthesis of caregiver interventions and techniques that were then converted into a protocol document. The purpose of the caregiver intervention protocol manual is to help occupational therapists build a program that can assist in improving the interaction between caregiver dyad members. Topics for the protocol document include: Home Safety/Environmental Interventions; Communication Strategies; Prevention of Negative Behaviors/Agitation; Educational Training/Skill Building, and Leisure Activities (Health & Medicine, 2013). Although the caregivers did not share large amounts of information regarding the importance of participation in leisure activities, the investigator did provide information regarding these activities based on current evidence.

Research Design

The focus of the third study was the development of a caregiver intervention protocol manual that would provide strategies to enhance a positive relationship between caregiving dyad members. The study entailed a program evaluation of the protocol manual. A program evaluation is a method to evaluate the design, implementation, improvement, and outcomes of a specific program (University of Washington, 2000).

Participants

Four occupational therapists whom the investigator knows personally were asked to review the interventions created from the data collected from the first two studies and provide feedback using a standardized tool which is described in the Data Collection Tools. The occupational therapists were at least 24 years of age and had a minimum of two years of experience including working with patients diagnosed with dementia and their caregivers. The occupational therapists are currently working or have worked in inpatient rehab facilities, home health agencies, skilled nursing facilities, acute care settings, or memory home units. All four occupational therapists who participated in the study were provided with code names: Occupational Therapist 1 (OT1), Occupational Therapist 2 (OT2), Occupational Therapist 3 (OT3), and Occupational Therapist 4 (OT4).

Data Collection Tools

A formal letter was sent to the four occupational therapists via email. The letter included the study's name, purpose of the research study, occupational therapists' role regarding the study, and the investigator's contact information if they had questions. An informed consent for their participation in the research study was sent via email and signed prior to participation in the study. The Appraisal of Guidelines, Research, and Evaluation II instrument (AGREE II) was sent via email to the occupational therapists. The AGREE II was used as a framework to evaluate the quality of interventions that were created from the data collected from the first 2 studies. The AGREE II assesses six quality domains: 1) scope and purpose, 2) stakeholder involvement, 3) rigor of development, 4) clarity and presentation, 5) applicability, and 6) editorial independence

(Don-Wauchope, Sievenpiper, Hill, & Iorio, 2012). For the purpose of this study, five out of six quality domains were used: scope and purpose; stakeholder involvement; rigor of development; clarity and presentation; and applicability.

The AGREE II follows a 7-point Likert Scale: 1-Strongly Disagree to 7-Strongly Agree (The AGREE Research Trust, 2013). A score of 1 should be provided when the information is not relevant to the AGREE II item or the idea is not stated clearly. Scores between 2 and 6 do not meet full criteria. The scores increase if more criteria are met. A score of 7 should be provided if the information meets full criteria or the quality of the information is stated clearly (The AGREE Research Trust, 2013). Every item on the AGREE II targets one key aspect of the practice guideline quality and two overall rating items, requiring the appraiser to make an overall assessment of the guideline (Don-Wauchope et al., 2012). The AGREE II Chronbach Alpha scores measure an internal consistency of the six domains ranging from 0.64 to .89 (Cluzeau, Burgers, Brouwers, & Grol, 2003, p. 21). Please see Appendix D for AGREE II.

Data Analysis and Results

AGREE II

Data analysis consisted of calculating the mean item scores from the completed AGREE II provided by each occupational therapist. The mean was calculated by averaging the scores across the responses of the four occupational therapists. The occupational therapists were also able to offer comments about the caregiver intervention protocol manual.

Results

AGREE II Scores. All items on the AGREE II provided by the four occupational therapists were added and divided by the total number of items on the tool to determine the mean scores. See table below for the mean scores for each occupational therapist.

Table 9

Occupational Therapist AGREE II Mean Scores

Occupational Therapists	AGREE II Mean Scores
OT1	6
OT2	7
OT3	7
OT4	6

Note. Scores between 2 and 6 do not meet full criteria. The scores increase if more criteria are met. A score of 7 should be provided if the information meets full criteria or the quality of the information is stated clearly.

Written Feedback

While scoring the items, the occupational therapists provided written feedback regarding the caregiver intervention protocol manual. Please see feedback below.

OT 1 comments were:

- “Rationale for research is stated. For clear clarification of objectives, an additional statement may be added to category III. (i.e. The objectives of this research is to identify interventions that may assist in decreasing stressors in caregivers of persons with dementia.)”
- “Only see caregiver age and self-identification criteria.”

- “Neither strengths or limitations of this research are addressed.”
- “Risks are not addressed clearly.”
- “It may be beneficial for clarity to rename categories.”

OT2 comments were:

- “Yes they are good interventions. They provide structure for the caregiver and client. It helps when there is a schedule to follow beginning from waking up at a certain time, performing ADLs (grooming, bathing, dressing), eating their meal and performing what other activities that they have scheduled. I know from both sides of incorporating these interventions as Occupational Therapist and a caregiver when caring for my own mother who had dementia. Being educated in what helps your love one and getting the support you need as a caregiver is paramount in surviving during this life experience.”

OT3 comments were:

- “I agreed with a majority of what I read. I would like to have seen more specific resources. So if I was to read your presentation/study, I would be able to take some of those resources and immediately apply to my practice.”

No comments provided by OT4.

When reviewing the occupational therapists’ mean scores, all agreed that the quality of the interventions is good, but recommended specific changes or recommendations to improve the interventions. These changes included: clearer objectives (i.e. The objectives of this research is to identify interventions that may assist

in decreasing stressors in caregivers of PWD; providing strengths and limitations of the interventions; stating the risks more clearly; and renaming categories for a better understanding.

Discussion

Findings showed, based upon the mean scores obtained from the AGREE II, that the occupational therapists thought the protocol manual could be useful in clinical practice for the purpose of educating caregivers to help improve positive relationships with PWD. However, they did remark that the manual requires more detailed information to improve the quality of the interventions that were described.

Limitations

One limitation was the minimum amount of occupational therapy participants in the sample. The small amount of participants limited the amount of feedback and information that could have been useful when developing the intervention protocol. If the sample population was larger, more feedback might have been provided to improve the quality of the protocol manual.

Conclusion

In conclusion, the data that emerged from the AGREE II scores provided information regarding the quality of the proposed interventions. It was found that although the occupational therapists agreed to these interventions being useful in clinical practice and caregiver education, the objectives, risks, names of categories, and strengths and limitations of interventions needed to be stated more clearly. Regarding the AGREE II, the tool was very user-friendly and would likely be used for future research.

CHAPTER VI

SYNTHESIS AND DISCUSSION OF THE THREE STUDIES

Family caregivers who care for a family member with dementia report that it is often difficult. They experience high levels of emotional stress and depression. Caregiving may also have a negative impact on physical health, employment, income and family finances (Pierce, 2012). As the older adult population increases, so will the number of adults living with dementia or Alzheimer's disease. Due to this increase, the need for occupational therapy intervention to support those with dementia or Alzheimer's disease and their caregivers will also increase (Zellner & Smallfield, 2016).

Occupational therapists can play an important role in supporting family caregivers and enhancing their ability to successfully provide care by incorporating the profession's recognition, respect, and appreciation of clients' and caregivers' opinions, preferences, experiences, and knowledge about their life situations. By emphasizing personal assets and coping skills, occupational therapists support self-efficacy and resilience, and help clients and family caregivers make the connection between past and successful strategies and current challenges. By reinforcing this support to client caregivers, their ability, in turn, to problem solve and manage their current and future situations is facilitated. (O'Sullivan, 2015).

Occupational therapists understand and appreciate the valuable role caregivers play in achieving successful outcomes with PWD. Caregivers play an important role in

the client care team and often help the occupational therapist develop meaningful interventions toward desired goals. Occupational therapists understand the importance of supporting caregivers in their role to minimize stress and burnout (Pierce 2012). There is moderate to strong evidence that supports specific occupational therapy interventions for PWD and their caregivers (Arbesman, Lieberman, & Metzler, 2014). These interventions include:

- Identifying occupational performance issues and helping clients implement compensatory and environmental strategies.
- Activities, such as leisure activities, tailored to PWD to improve participation and satisfaction.
- Compensatory and environmental strategies which include cueing and step-by-step instructions to improve participation in activities and reduce caregiver burden.
- Caregiver education, including problem solving techniques and technical skills (task simplification, communication), simple home modifications, and stress management, to reduce caregiver burden and increase caregiver self-efficacy.
- Strategies to manage the physical environment to encourage participation in daily activities.
- Sleep routine strategies to manage daytime activities and nighttime sleeping, including voiding strategies for toileting to help prevent sleep disturbances (Arbesman et al., 2014).

These interventions could help improve quality of life for both the caregiver and care receiver (AOTA, 2014).

The intent of this research study was to explore the benefits of caring for PWD and develop an approach for occupational therapy to facilitate possible positive dimensions of caregiving. There were three aims that helped guide this study. The first aim explored caregivers' perspectives on experiences of caring for a family member with dementia by collecting data from caregivers using the PCRS, an interview guide, and a focus group. The second aim examined ways in which occupational therapy currently facilitates positive dimensions of care by collecting data from occupational therapists by using an interview guide. The last aim was the development of an intervention protocol based on the data collected from the first two studies and current supportive evidence.

The guiding theoretical model for this dissertation work was the Person Environment Occupation (PEO) model (Tsunaka & Chung, 2012). The first study was a mixed methods design guided by the PEO model through the use of an interview guide, PCRS, and focus group to understand caregivers' perspectives and experiences with caring for a family member with dementia; identify specific rewards of caregiving to help determine interventions that could be of help to other caregivers experiencing burden of care while caring for a PWD within a supported physical environment. The second study was a phenomenological study design that was guided by the PEO model through the use of an interview guide by identifying occupational therapists' experiences with caregiving dyad members; identify interventions that have been successful in improving satisfaction and positive relationships between caregivers and PWD while in a health care facility.

The third study was the development of a caregiver intervention protocol that was also guided by the PEO model. This intervention protocol was developed for occupational therapists to improve interaction between caregivers and PWD within a supported physical environment. The data collected from the first two studies helped develop the caregiver intervention protocol manual.

While developing the protocol manual, the investigator utilized the occupational profile to gather information about caregivers. The occupational profile is an assessment that provides occupational therapists an understanding of the person's occupational history, experiences, patterns of daily living, interest, values, and needs (Brennan, McGuire, & Metzler, 2016). The occupational profile helped to evaluate the caregiver's role identity and understand their expectations of the role. Identifying caregivers' values and needs and any barriers to accomplishing their roles can be helpful in designing meaningful interventions (Williams, 2016). Below is a table that provides a guide to assessing caregivers' identity using the occupational profile.

Table 10

Assessing Caregiver Identity Through the Occupational Profile

<p>History and Experiences</p> <ul style="list-style-type: none"> - Age, gender, personality, relationship dynamics to care recipient, mental and health status - Presence of stress triggers for harmful behaviors
<p>Interests and Values</p> <ul style="list-style-type: none"> - Supported or changed by the caregiver role - Ability and frequency of engagement in desired and leisure activities
<p>Performance Patterns: Roles and Daily Living Patterns</p> <ul style="list-style-type: none"> - Level of care provided to the care recipient - Roles currently engaged in; caregiver role identified - Successes and barriers to carrying out care tasks - Feelings of role competence versus role challenges
<p>Needs and Priorities</p> <ul style="list-style-type: none"> - Are needs being acknowledged and met? - Frequency of engagement in health preventative behaviors
<p>Environment</p> <ul style="list-style-type: none"> - Barriers to performing caring tasks: physical, emotional, financial - Need for modifications or simplifications
<p>Support</p> <ul style="list-style-type: none"> - Access to and eligibility for resources and respite - Perceived level of support is adequate vs. lacking - Comfort level and ability to recruit support

Note. (Williams, 2016; retrieved from Framework; AOTA, 2014. P. S13)

Summary of Results

The results of the first study allowed the investigator to examine the information from the PCRS scores and focus group information. Each caregiver had a mean score of “3” or “quite a lot” which describes their positive experiences with caregiving. The caregivers also did provide a score of “4” or “A great deal” on certain questions on the PCRS. These questions looked at how satisfied they were with healthcare providers; tolerance to people with disabilities; receiving affection such as a touch or smile from

their loved one; ability to learn new information during this experience; and having the freedom to make decisions that matter to them. All caregivers had positive responses to these questions and provided advice to other caregivers who were going through the same experience.

The results of the second study consisted of analyzing the information to find similar responses from the occupational therapists' interviews. Based on the occupational therapists' responses, the investigator developed two tables: A Demographic Table and Table of Occupational Therapy Interventions. The tables were developed to help organize information and to identify and describe common patterns among the therapists' responses. Protocol topics were developed based on those patterns including: Person Strategies, Environment Strategies, Occupations, and Resource Strategies for family caregivers. Ultimately, the investigator was able to synthesize these patterns for the caregiver intervention protocol manual. The protocol manual was developed using several categories that were formed based on the data collected and current supportive research. These categories included: Home Modifications, Communication Interventions, Interventions to decrease Negative Behaviors, Education Training, and Leisure Activities. The results from the third study consisted of the four occupational therapists providing feedback using the AGREE II scale. The mean scores on the AGREE II were calculated for each occupational therapist. The scores ranged from 6 to 7 which determines the quality and clarification of the intervention created based on the data collected from the first two studies. The occupational therapists also provided detail written feedback regarding the interventions. After reviewing the occupational therapists' feedback, all

agreed that the quality of the interventions are good but lacked clarity regarding objectives, strengths and limitations, and risks.

Limitations of the Study

The investigator acknowledges that there are limitations to this research. One area of concern is the limited amount of participants. This restricted the amount of information that could have been utilized to develop a more detailed caregiver intervention protocol manual. Other limitations are the data came from only one focus group and the lack of diversity/not having participants from various ethnic backgrounds. Such diversity would have provided greater variety and richer perspectives on caregiving and, in turn, could have possibly provided a more descriptive protocol manual.

Clinical Practice

This research study focused on family caregivers who were husbands or wives of a family member with dementia. Research has shown that spouses who are the primary caregivers represent an extended period of exposure to stressors and losses brought about from the effects of caring for a spouse with dementia. A number of researchers, specifically caregiving researchers and service providers, have observed that this exposure increases caregivers' vulnerability to depression (Adams, 2008). It is important that in clinical practice, practitioners such as occupational therapists, need to provide interventions to caregivers that help alleviate this type of psychological adverse outcome. It was the intent of this research study to develop a protocol manual that could be used in clinical practice to alleviate burden and improve satisfaction with caregiving, specifically for caregivers who care for a family member with dementia.

Future Research Directions

Future research directions that should be considered is obtaining a larger sample size that includes various cultures, religious beliefs, and ethnic backgrounds. Exploring how diversity influences the caregiving experience on factors of burden of care, satisfaction with care, and interventions may be of help to other caregivers of similar backgrounds. Another future direction could be to determine how caregivers perceive burnout, and if this is a main determinant for placement. Also, recruiting caregivers beyond the usual organizations or university clinics, such as churches, stores, beauty salons, and /or medical clinics, to identify key informants in the community would help expand the recruitment process (Berg-Weger & Tebb, 2003/2004).

Conclusion

In conclusion, the objective of this research study was to develop a protocol manual of caregiver interventions to assist occupational therapists with strategies that enhance a positive relationship between caregiving dyad members. The study's strengths are the rich, detailed information provided by the participants; length of time the CGs cared for the CR which contributed to the detailed information provided in the focus group interviews; and occupational therapist experiences with PWD and their caregivers which allowed for beneficial information from the interviews. Future research may generate further questions and potential study on caregiving dyad members. Similar studies conducted by occupational therapists would certainly benefit caregivers who are experiencing the stress of caregiving to consider the positives of caregiving.

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Appendix A
Picot Caregiver Reward Scale

Choose only one answer for each statement from the following:

A great deal (4), Quite a lot (3), Somewhat (2), A little (1), Not at all (0).

	Great Deal	Quite a lot	Somewhat	A little	Not at all
1. I feel God will bless me.	4	3	2	1	0
2. I feel better about myself.	4	3	2	1	0
3. I feel I have become a stronger, tolerant, and/or patient person around persons with sickness or disabilities.	4	3	2	1	0
4. I feel having others say that taking care of my relative is the right thing to do is important.	4	3	2	1	0
5. I feel that my relative will remember me in his/her will for my care.	4	3	2	1	0
6. I feel someone will take care of me when I need it.	4	3	2	1	0
7. I feel nurses, doctors, and social workers work harder to care for my friend/relative too.	4	3	2	1	0
8. I feel that placing my friend/relative in a nursing home will be avoided.	4	3	2	1	0

9. I feel that doctors, nurses and social workers do not know everything about my friend/relative's chances for getting better.

4 3 2 1 0

10. I receiving a smile, touch, or eye contact from my friend/relative is important.

4 3 2 1 0

11. I feel I have a closer relationship with my friend/relative.

4 3 2 1 0

12. I feel I have an opportunity to repay my friend/relative for a past debt.

4 3 2 1 0

13. I feel receiving a "thank you" from my friend/relative is important.

4 3 2 1 0

14. I feel I have become a better person by learning new information.

4 3 2 1 0

15. I feel I have become a better person by learning new ways to care for the elderly.

4 3 2 1 0

16. I feel that I have made many new friends.

4 3 2 1 0

17. I feel more important.

4 3 2 1 0

18. I feel I have the freedom to make decisions that matter.

4 3 2 1 0

19. I feel I don't need to hold a job.

4 3 2 1 0

20. I feel that receiving praise and admiration for my efforts from doctors, nurses and a social worker is important.

4 3 2 1 0

21. I feel I can now plan my own schedule each day.

4 3 2 1 0

22. I feel happier now than I did before I started caring for my friend/relative.

4 3 2 1 0

23. I feel that caring for my friend/relative has made our family grow and work closer together.

4 3 2 1 0

24. I feel my family members now look up to me because of my efforts under difficult circumstances.

4 3 2 1 0

Appendix B
Focus Group Interview Guide

Refreshments will be served prior to the beginning focus group interview to welcome participants. Ten minutes will be allowed for this preliminary part of the session.

Introduction:

1. Welcome
2. Overview of the topic
3. Rules (Explain what a focus group is and how it will be conducted)

Interview Questions

1. I would like to begin by going around and asking each of you to tell us a little about yourself including a fun fact (allows participants to relax a little/letting go of some nervous energy)
2. How long have you been caring for your family member?
3. What influences or encourages you to be a caregiver?
4. What are some challenges about caring for a family member with dementia/Alzheimer's?
5. How do you deal with these challenges you have mentioned?
6. How have you been able to limit the amount of stress or burden with caring for a family member with dementia?
7. What type of support do you have to help decrease stress with caring for a family member with dementia/Alzheimer's?

8. What are some benefits about caring for a family member with dementia/Alzheimer's?
9. What have you learned about yourself as person since caring for a family member with dementia/Alzheimer's?
10. Compare your relationship with your family member now to when you first started as their caregiver.
11. What type of education or advice would you give to other caregivers regarding caring for a family member with dementia/Alzheimer's?
12. Anything else you would like to share regarding your experience as a caregiver?

Appendix C

OT Practitioner Interview Guide

The introduction will include a detailed synopsis of the study. Then I will ask if they have any questions pertaining to the study.

1. How long have you been an Occupational Therapist?
2. What has your experience been like regarding working with patients who have dementia?
3. What are some interventions that you have implemented in your treatment sessions with patients with dementia that have been successful?
4. What type of experiences have you had with caregivers, specifically those caring for family members with dementia?
5. What type of interventions or education have you provided to caregivers regarding limiting their amount of stress with caring for a family member with dementia?
6. What type of interventions or education have you provided to caregivers to help maintain positive relationships between themselves and their family member with dementia?
7. Any other comments or thoughts you care to share?

Appendix D

Appraisal of Guidelines for Research and Evaluation II (AGREE II)

Please rate each item below using the following 7-point scale. Comments can to be added to clarify rating.

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

Scope and Purpose

- ___ 1. The overall objectives of the protocol are described specifically.
- ___ 2. The health questions covered by the protocol are described specifically.
- ___ 3. The population to whom the protocol is meant to apply is described specifically.

Stakeholder Involvement

- ___ 4. The protocol development group includes individuals from all relevant professional groups.
- ___ 5. The views and preferences of the target population have been sought.
- ___ 6. The target users of the protocol are defined clearly.

Rigor of Development

- ___ 7. Systematic methods were used to search for evidence.
- ___ 8. The methods used for formulating the protocol are described clearly.
- ___ 9. The strengths and limitations of the body of evidence are described clearly.
- ___ 10. The protocol was reviewed before its publication.
- ___ 11. The health benefits, side effects, and risks have been considered in

formulation the recommendations.

___ 12. There is an explicit link between the recommendations and the supporting evidence.

___ 13. The protocol has been externally reviewed by experts prior to its publication.

Clarity of Presentation

___ 14. The recommendations are specific and unambiguous.

___ 15. The different options for management of the condition or health issue are clearly presented.

___ 16. Key recommendations are easily identifiable.

Applicability

___ 17. The protocol provides advice and/or tools on how the interventions can be put into practice.

Appendix E

Caregiver Intervention Protocol Manual

AN OCCUPATIONAL THERAPY PROGRAM MANUAL FOR ENCOURAGING
POSITIVE CAREGIVING EXPERIENCES

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CHAPTER I

INTRODUCTION

Approximately 5.2 million Americans have some form of dementia and this alarming situation is expected to rise (Crowe, 2015). Persons with dementia (PWD) exhibit a wide range of symptoms such as a decline in memory, thinking or problem solving skills, and motor skills that reduces their ability to perform daily activities (Alzheimer's Association, 2017). Due to this decline in cognition and motor skills, the PWD will require some level of assistance. Research has shown that as the dementia progresses, the level of assistance and supervision increases. Family caregivers are most likely to provide this level of assistance (Piersol, Earland, & Herge, 2012).

O'Sullivan (2015) defines family caregivers as any relative, partner, friend, or neighbor who provides a broad range of assistance to adults with disabling conditions such as dementia. Caregivers can experience negative effects with the role of caregiving such as stress, depression, emotional upset, anxiety, poor physical and emotional health, and decreased quality of life. The responsibilities that come with caregiving disrupt employment, leisure exploration, and social participation. Caregiver stress frequently increases when the person with dementia manifests challenging behaviors that typically develops as the disease progresses. These behaviors include agitation, wandering, refusing care, destructive behaviors, physical agitation, verbal agitation, hoarding, or distressful feelings. Research suggests that family caregivers find these behaviors difficult to manage (Piersol et al., 2012).

Occupational therapists play an important role in supporting family caregivers and enhancing their ability to successfully provide care. Occupational therapists help families understand the dementia disease process, set up or modify daily routines, provide training on effective strategies to manage behaviors, and teach family caregivers ways to reduce their own stress and take care of themselves (Piersol et al., 2012). Occupational therapists can help family caregivers regain a sense of control over their lives. The caregiver's occupational needs and role demands must be incorporated into the occupational therapists' interventions with care recipients (O'Sullivan, 2015).

The goal of this protocol manual is to provide an approach for occupational therapists that offers effective interventions to facilitate positive feelings of caregiving and to maintain positive relationships between caregiving dyad members. This protocol manual provides a comprehensive description of interventions that were determined based on dissertation findings. The data collection tools that were used to develop the recommendations and interventions included occupational therapist and caregiver interview guides, a focus group, the Picot Caregiver Reward Scale (PCRS) scores, and current research evidence.

CHAPTER 2.

Evaluation Process using The Occupational Profile

Prior to providing an intervention to caregivers, occupational therapists must perform an evaluation to gather information using the occupational profile (AOTA, 2014). The occupational profile is an assessment that provides occupational therapists an understanding of the person's occupational history, experiences, patterns of daily living, interest, values, and needs (Brennan, McGuire, & Metzler, 2016). This assessment also allows for evaluating caregiver identity and understanding the caregiver's expectations of the role. The evaluation process should also include an activity analysis of the caregiver's occupational performance. This will allow the occupational therapist to collect and interpret information that can identify supports and barriers related to his or her performance and any targeted outcomes (AOTA, 2014). Identifying caregivers' values, needs, and role barriers can be helpful in designing meaningful interventions (Williams, 2016). Below is a table that will help guide the occupational therapist in assessing caregiver identity, experiences with caregiving, and supportive needs.

Assessing Caregiver Identity Through the Occupational Profile

(Williams, 2016; retrieved from Framework; AOTA, 2014. P. S13)

History and Experiences
<ul style="list-style-type: none">- Age, gender, personality, relationship dynamics to care recipient, mental and health status- Presence of stress triggers for harmful behaviors
Interests and Values
<ul style="list-style-type: none">- Supported or changed by the caregiver role- Ability and frequency of engagement in desired and leisure activities
Performance Patterns: Roles and Daily Living Patterns
<ul style="list-style-type: none">- Level of care provided to the care recipient

<ul style="list-style-type: none"> - Roles currently engaged in; caregiver role identified - Successes and barriers to carrying out care tasks - Feelings of role competence versus role challenges
<p>Needs and Priorities</p> <ul style="list-style-type: none"> - Are needs being acknowledged and met? - Frequency of engagement in health preventative behaviors
<p>Environment</p> <ul style="list-style-type: none"> - Barriers to performing caring tasks: physical, emotional, financial - Need for modifications or simplifications
<p>Support</p> <ul style="list-style-type: none"> - Access to and eligibility for resources and respite - Perceived level of support is adequate vs. lacking - Comfort level and ability to recruit support

CHAPTER 3.

Home Environmental Modifications

Struckmeyer and Pickens (2016) define home modifications as a variety of strategies including structural renovation, assistive devices, placement of visual cues, memory aids, and rearranging or removing furniture and dangerous household items. Acknowledging the importance of space and objects will help engage caregivers and care receivers and allow the therapist to make recommended changes to the environment and to ensure they are acceptable to the family. If modifications or assistive technology are needed, the occupational therapist can make a referral to Agency on Aging or other community providers to identify potential funding resources (O'Sullivan, 2015)

These modifications are intended to increase use, safety, security, and independence. When performing home modifications, it is important that occupational therapists evaluate; identify and implement solutions; and train the caregivers (Struckmeyer & Pickens, 2015).

Below is a list of interventions that occupational therapists can provide to caregivers that will make their environment safe and alleviate worry or stressful situations.

Home Safety and Environmental Interventions

- Eliminating or decreasing barriers in the home: providing a well-lit environment, removing items that could be a potential fall risk (thin rugs, anti-slip mats inside and outside shower/tub).



- Structuring ADL/self-care tasks to include performing the same tasks (brushing teeth, bathing, dressing, eating) at the same time daily.
- Set-up self-care tasks (as appropriate to cognitive needs) in the same place daily before self-care tasks are performed to improve independence and decrease distraction.



Hiring additional assistance to help with self-care ADLs, specifically with bathing and to help prevent falls from occurring. A Home Health Aide who is consistent and reliable can be a positive contribution to lessening caregiver stress.

- Different locks on the door such as double deadbolt to prevent wandering outside home environment.



These home modification interventions will allow occupational therapists to help caregivers make the environment safer by preventing falls, wandering; and support occupational engagement which, in turn, will lessen caregiver stress.

CHAPTER 4.

Communication with Persons with Dementia (PWD)

Dementia causes changes in areas of the brain that causes problems with communication.

The need to improve communication strategies with PWD by family caregivers and practitioners is three-fold. First, a growing body of evidence suggests that improved communication with a PWD has a positive effect on the person's quality of life. Second, improved communication with the person who has dementia can lessen the burden on the caregiver resulting in increased quality of life for them. Third, improved communication practices within all health care environments is essential, in view of the increasing number of persons with dementia and the societal and financial costs of providing health care services to them. Occupational therapists are highly qualified to train caregivers in specific communication skills. They can coach caregivers on how to use practical strategies, a combination of visual cues (gestures, picking up a prop to indicate action, use fewer words, or move your bodies), shorter sentences, and a focus on the emotional tone of one's voice (McKay & Hanzaker, 2013).

Below is a list of communication interventions that occupational therapists can provide to caregivers that will help lessen the burden of care and increase their quality of life.

Communication Interventions

- Using simple commands (1-2 word commands) so the person with dementia is able to understand you better.
- Large visual aids with basic/simple instructions or pictures showing how to perform simple ADL tasks. Pictures that will allow the person with dementia to understand what is expected of them.



- Simple demonstration (Make sure demonstration is short and fun) to help with maintaining attention.

Occupational therapists can educate caregivers on the above communication strategies to help them communicate more effectively with the care receivers.

CHAPTER 5.

Behavior and Dementia

Occupational therapists should expect to work with PWD and their caregivers now and into the future (Piersol et al., 2012). Over time non-cognitive behavioral symptoms occur across all types and stages of dementia affecting 98% of individuals. As cognitive ability declines, there is a heightened vulnerability to the environment that can manifest in behavioral symptoms (Corcoran et. al, 2002). These symptoms include: agitation, wandering, resisting care, destructive behaviors, catastrophic reactions or excessive agitation such that can place the caregiver at risk of physical or verbal abuse (Piersol et al., 2012). Caregivers have shown difficulty with managing these behaviors which can lead to excessive burden of care. Because of the difficulty they experience with managing these behaviors, caregivers are at risk for poor emotional health such as depression and anxiety which, in turn, can affect their quality of life (Corcoran et. al, 2002).

Occupational therapists are in a position to help families understand the disease process modify or adapt daily routines, provide training or education strategies to manage difficult behaviors, and teach caregivers ways to reduce adverse effects of caregiving such as stress and learn to take better care of themselves (Piersol et al., 2012).

By occupational therapists providing these strategies, such an approach could help potentially modify the disease course, lower costs, and improve quality of life for caregivers (Kales, Gitlin, & Lyketsos, 2014).

Below is a list of interventions occupational therapist can use to educate caregivers on ways to decrease excessive disruptive behaviors while caring for a PWD.

Interventions for Decreasing Behavior Symptoms

- Provide increased PRAISE for tasks completed to give a sense of worthiness and independence.
- Keep certain routines at the same time to prevent potential frustration.
- Identify and understand the triggers that may cause negative behaviors and/or agitation and attempt to eliminate those triggers.



CHAPTER 6.

Occupational Therapy and Educating Caregivers

Occupational engagement has been found to help improve the well-being of caregivers and improve satisfaction with caregiving. Ways to improve occupational engagement is educating or providing information on community resources or services.

Below is a list of education strategies occupational therapists can provide to caregivers.

Educational Training/Skill Building Interventions

- Seek out community and financial resources such as specialized Alzheimer's adult day care centers, respite care, veterans aid, meals on wheels, and via trans.



- Understanding the stages of Alzheimer's. Learn more about Alzheimer's/dementia so you are able to prepare yourself as the disease progresses.

- Understanding and knowing the different types of facilities and the level of care/assistance (visiting those facilities; requesting guidance by a healthcare professional) they are able to provide when trying to decide on placement.
- Stress the importance of involvement in their local support groups to discuss experiences, ideas, and provide emotional support for each other.



These strategies or interventions will allow occupational therapist to help caregivers understand that there are community resources out there that can help provide the support they need, alleviate caregiver stress, and improve the relationship with the care receiver.

CHAPTER 7.

Engagement in Occupation

Engagement in occupation is defined as activities that are related to a person's life roles which plays a significant role in health and well-being. Older adults have expressed that being able to retrain a role in society or family are central to the quality of life. However, the progressive cognitive and functional impairments that happen with dementia greatly restrict optimal and meaningful engagement in activities. People with dementia rely heavily on caregivers for their performance of many activities including everyday tasks and socially related activities (Tsunaka & Chung, 2012).

The Occupational Therapy Practice Framework: Domain & Process 3rd Edition (2014) defines engagement in occupations as:

“Performance of occupations as the result of choice, motivation, and meaning within a supportive context and environment. Engagement includes objectives and subjective aspects of clients’ experiences and involves the transactional interaction of the mind, body, and spirit. Occupational therapy intervention focuses on creating and facilitating opportunities to engage in occupations that lead to participation in desired life situations.” (p. S4)

Enhancing Participation in Leisure Activities

Participation in leisure activities has been associated with better quality of life.

Caregivers who participate in enjoyable leisure activities will have better and psychosocial and physical health. Research shows that leisure engagement is important for continuing social relationships, building new connections, and maintaining identity.

Physically active leisure activities have been associated with better physical health and sleep quality among older caregivers. Leisure activities including sports/recreation, socialization with friends, hobbies, and other activities that contribute to friendships help with mental and physical wellbeing of caregivers (Kniepmann,

2014).



In conclusion, this manual was developed to help occupational therapists build a program to improve positive relationships between caregivers and care receivers through the use

of specific strategies including home modifications, proper communication strategies, managing negative behaviors, education training, and involvement of leisure activities.

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Appendix F
Caregivers Consent to Participate in Research Study

Title: Caring for a Family Member with Dementia: An Occupational Therapy Approach to Facilitate Positive Dimensions of Caregiving

Investigator: Precious Osuoha.....posuoha@twu.edu 972-xxx-xxxx
Advisor: Gayle Hersch, PhD, OTR.....ghersch@twu.edu 713-7xxx-xxxx

Explanation and Purpose of the Research

You are being asked to participate in a research study for Precious Osuoha at Texas Woman's University. The purpose of this research is to explore the benefits of caring for a person diagnosed with dementia and develop an intervention plan for occupational therapy that increases the positive aspects of caregiving. You have been asked to participate in this study because you are a caregiver who cares for a family member diagnosed with dementia who is living in a residential setting.

Description of Procedures

As a participant in this study you will be asked to spend 1 hour in a focus group and approximately 1 to 1.5 hours in an individual interview. The total amount of time spent in focus group and individual interviews will be 2 to 2.5 hours. The individual interview will entail: a discussion of the research study; obtaining an informed consent for your participation; and completion of the Picot Caregiver Reward Scale (PCRS). The focus group will consist of several caregivers who will be asked questions about their caregiving experiences. Each individual will be asked to explain their answers recorded on the PCRS. The focus group will be audiotaped and transcribed for analysis. The purpose for the focus group is to identify and examine key points that could be of help to other caregivers who are experiencing burden with caring for a person with dementia and/or benefits of caregiving. You and the researcher will decide on a code name for you to use during the focus group and for the interview.

Potential Risks

Possible risks in this study are loss of confidentiality, loss of time, and emotional involvement. Loss of confidentiality will be minimized by the following steps. Names will not be used: you will be addressed by your code name. All data that is collected will be stored in a locked cabinet in the investigator's office. Only the research team members will have access to the data. Audio-recordings, written information, and signed forms will be shredded after the study is completed. To minimize loss of time, interviews and focus

group will be scheduled at times that are appropriate and convenient for facility and participants. The investigator will be prepared so no additional time is taken or needed from you. To minimize emotional involvement, you may take rest breaks or withdraw from the study at any time without question or penalty. A resource list will be offered for additional help.

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Appendix G
Occupational Therapist Consent to Participate in Research Study

Title: Caring for a Family Member with Dementia: An Occupational Therapy Approach to Facilitate Positive Dimensions of Caregiving

Investigator: Precious Osuoha.....posuoha@twu.edu 972-xxx-xxxx

Advisor: Gayle Hersch, PhD, OTR.....ghersch@twu.edu 713-7xx-xxxx

Explanation and Purpose of the Research

You are being asked to participate in a research study for Precious Osuoha at Texas Woman's University. The purpose of this research is to explore the benefits of caring for a person diagnosed with dementia and develop an intervention plan for occupational therapy that increases the positive aspects of caregiving. You have been asked to participate in this study because you are an occupational therapist who has worked with persons with dementia and their caregivers.

Description of Procedures

As a participant in this study you will be asked to spend 1 hour in a individual interview and, if you choose to review the intervention protocol, an additional 1 to 1.5 hours will be required. The total amount of time spent in the individual interview and/or review of the intervention protocol will be 1 to 2 to 2.5 hours. The individual interview will consist of a formal open-ended questionnaire related to your experience with persons diagnosed with dementia and caregivers on techniques or interventions you have used to decrease burden and enhance satisfaction of care. The researcher will develop an intervention protocol based on caregivers' responses from Picot Caregiver Reward Scale (PCRS), focus group discussions, and the individual interview responses. The intent of the intervention protocol will be to facilitate occupational therapists in enhancing positive relationships between people with dementia and their caregivers. Once the researcher has completed the suggested list of interventions and techniques, three to four occupational therapists will provide feedback using the Appraisal of Guidelines, Research, and Evaluation II instrument (AGREE II). You and the researcher will decide on a code name for you to use during the individual interview and review of the intervention protocol.

Potential Risks

Possible risks in this study are loss of confidentiality, loss of time, and emotional involvement. Loss of confidentiality will be minimized by the following steps. Names will not be used: you will be addressed by your code name. All data that are collected will be stored in a locked cabinet in the investigator's office. Only the research team members will have access to the data. Audio-recordings, written information, and signed forms will be shredded after the study is completed. To minimize loss of time, interviews and review of

the intervention protocol will be scheduled at times that are appropriate and convenient for facility and participants. The investigator will be prepared so no additional time is taken or needed from you. To minimize emotional involvement, you may take rest breaks or withdraw from the study at any time without question or penalty.

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The researchers will try to prevent any problem that could occur because of this research. You should let the researchers know at once if there is a problem and they will help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

Participation and Benefits

Your involvement in this study is completely voluntary and you may withdraw from the study at any time. Following the completion of the study no financial remuneration will be provided. Information from the intervention protocol may be share if requested. If you would like to know the results of this study the investigator will mail them to you.

Questions Regarding the Study

You will be given a copy of this signed and dated consent form to keep. If you have any questions about the research study you should ask the researchers; their contact information is at the top of this form. If you have questions about your rights as a participant in this research or way this study has been conducted, you may contact the Texas Woman’s University Office of Research at 713-794-2480 or via email at IRB@twu.edu.

Signature of Participant _____
Date

*If you would like to know the results of this study tell us where you want them to be sent:

Email: _____

or

Address:

Appendix G
Letter to Occupational Therapists

Dear _____:

My name is Precious Osuoha, a doctorate candidate in the School of Occupational Therapy at Texas Woman's University. I have selected to study caregivers of family members with dementia. The name of my study is, "Caring for a Family Member with Dementia: An Occupational Therapy Approach to Facilitate Positive Dimensions of Caregiving."

The purpose of the research study is to explore the benefits of caring for a person diagnosed with dementia and develop an approach for occupational therapy to facilitate any possible positive dimensions of caregiving. Specific objectives are to: explore different caregivers' perspectives on experiences of caring for a family member with dementia; examine ways in which occupational therapy currently facilitates positive dimensions of care; and develop an intervention protocol for occupational therapy that may help enhance positive relationships between caregivers and their loved ones with dementia.

The occupational therapists' responsibilities are: signing a formal consent form for participation in the research study; participation in a individual interview; and providing feedback on the intervention protocol utilizing Appraisal of Guidelines, Research, and Evaluation II instrument (AGREE II).

If you have any questions or interested in participating in the research study, please respond in 7 – 10 days via email: xxxxxxxx@yahoo.com or phone number: 972-xxx-xxxx. Your participation is greatly appreciated.

Thank you,

Precious Osuoha
PhD Candidate