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Boston University

BOSTON UNIVERSITY
SARGENT COLLEGE OF HEALTH AND REHABILITATION SCIENCES

Doctoral Project

**IMPROVING THE CARE PARTNER EXPERIENCE:
AN OCCUPATIONAL THERAPY INTERVENTION FOR
PEOPLE WITH DEMENTIA**

by

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B.A., University of New Hampshire, 1993

Submitted in partial fulfillment of the
requirements for the degree of
Doctor of Occupational Therapy

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Dedication

This dissertation is dedicated to my husband and children who put up with two years of stress and craziness to allow me to work on myself and my career goals. Thank you Michael, Josh, Jacob and Rhiannon, I love you to the moon and back. Also to my parents who raised me to believe I could accomplish anything I set my mind to. Dad, I hope you can see this—I miss you.

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**IMPROVING THE CARE PARTNER EXPERIENCE:
AN OCCUPATIONAL THERAPY INTERVENTION FOR
PEOPLE WITH DEMENTIA
DANIELLE MARIE AMERO**

Boston University, Sargent College of Health and Rehabilitation Sciences, 2018

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ABSTRACT

Improving the Care Partner Experience: An Occupational Therapy Intervention

proposes a clinic or telehealth based occupational therapy (OT) treatment intervention to teach care partners how to maximize the occupational engagement of care recipients diagnosed with Alzheimer's disease and related dementias and decrease caregiver burden. Caregiver burden contributes to care partner illness and care recipient institutionalization. The intervention consists of a protocol that is both client-centered and designed to foster self-efficacy of the care partner in providing care. A sense of self-efficacy will decrease caregiving burden and improve quality of life for both partners as described in the evidence supporting the project. The first chapter provides an overview of the intent and genesis of the intervention. It includes a description of the author's work environment, the problem as it was identified and how the intervention fits within the OT practice framework. The next chapter explores factors contributing to the problem including the rural nature of New Hampshire, barriers to accessing adequate treatment and the theoretical basis grounded in Self-efficacy theory and the Model of Human Occupation. The second half of the chapter explores current best practice that exists in

the literature. Several programs and interventions are identified and their efficacy is discussed. Based on the findings in chapter two, the intervention itself is outlined in chapter three, with examples of templates and a case scenario available in the appendices. The intervention, administered in the clinic or via telehealth, is based on the evidence of effective treatment in the home, translated into a clinic or telehealth-based model. Administration of the program is fully described and reproducible from this document. Finally, a plan for program evaluation along with a budget and dissemination plan are included in the final chapter. The result is an evidenced based, client-centered occupational therapy treatment that can be administered in a consistent manner and contribute to lower caregiver burden and increased quality of life.

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Chapter One: Introduction

What is the problem I propose to address and what outcome do I seek?

My practice at a community hospital includes performing cognitive evaluations to determine home safety and recommend a level of supervision for safety. While the referral to occupational therapy is for an evaluation only, a significant amount of time is spent explaining the findings to the care partner of the person experiencing cognitive decline. Often the person being evaluated no longer participates in basic or instrumental activities of daily living (ADL, IADL), or leisure occupations. According to the Alzheimer's Association (2017), common symptoms of Alzheimer's include challenges in planning and problem solving, difficulty completing familiar tasks at work and at leisure, and withdrawal from social activities. Giebal, Sutcliffe, and Challis (2017) identified a decrease in initiation prior to a decline in ability to perform the ADL or IADL. In other words, the person with dementia does not start an activity even if their functional skill is preserved. The care partner may perceive this as stubborn or obstinate behavior. Similar to evidence that shows care partners struggle to support people with dementia (Alzheimer's Association, 2017; Cepoiu-Martin, Tam-Tham, Patten, Maxwell and Hogan, 2016), in my practice I have noticed care partners unprepared to care for the person with dementia in a supportive manner that facilitates function. Unfortunately, our clinic does not currently have programming directed at remediating this problem.

Gitlin, Marx, Stanley, and Hodgson (2015) provide data that support there is a lack of programming. They find that the translation of research for evidence-based dementia interventions is at one percent while the translation rate for other medical based

research is 15 percent. Further compounding the problem, the bulk of the programming in the evidence focuses on intervention that takes place in the home (Padilla, 2011). In my practice, clients are not considered home bound for reimbursement purposes and receive outpatient services. Further, they often live in rural areas of New Hampshire with limited access to transportation and services. Clients will travel up to two hours to attend appointments in the geropsychiatry clinic at the hospital.

I intend to develop an intervention that is outpatient clinic or telehealth based to address care partner skills promoting the highest functional level of the care recipient, focusing on participation in ADL, IADL and leisure activities. Using the current evidence of effective interventions in the home setting, I will create an outpatient protocol with a frame work for evaluation and treatment intervention. An increase in quality of life for both the care partner and care recipient, a decrease in caregiver burden and promotion of maximal engagement for the person with dementia represent the desired outcomes of the intervention. In keeping with the scope of OT practice, the intervention will have the flexibility to be client-centered and focus on the ability, priorities and goals of each dyad.

Why does this problem matter? What are the consequences to clients (individuals, families, or professional group)?

The number of people diagnosed with Alzheimer's will increase 45% in the state of New Hampshire by 2025. In the United States, there are currently five million people diagnosed with Alzheimer's and 15 million people who act as informal care partners (Alzheimer's Association, 2017). Our facility has seen an increased need for

geropsychiatry medical providers, hiring 2 additional Advanced Practice Registered Nurses (APRN's) this year with 3 physicians and one Advance Practice Registered Nurse (APRN) currently on staff. The OT department has been doing more cognitive performance/safety evaluations on an outpatient basis than in previous years. The evaluation uses measures of ADL skills, cognitive levels and executive function. The health care providers often, but not always, use the Montreal Cognitive Assessment (MoCA) or the MiniMental State Examination (MMSE) as routine practice in their evaluation before referring to OT. Evidence suggests that impaired performance on memory and executive function tests predict increased risk of self-harm from neglect or poor self-management in the home (Tierney, 2007).

Further, many people with Alzheimer's live with family members, who work long hours caring for their family member and are not paid for the care. According to the Alzheimer's Association (2017), 30 to 40 percent of care partners of people with dementia are depressed, twice as many of these care partners report substantial physical and financial distress and 59 % rate the emotional stress as high to very high when compared to caregivers of other illnesses. The Association estimates that the healthcare to address illness from caregiver burden costs the healthcare system 10.9 million dollars. Therefore, caregiver burden is a significant issue. In addition, aging in place, or in the home, is more cost effective than nursing home placement (Marek, 2012) and often more desirable to the client and family. Buhr, Kuchibhatla, and Clipp (2006) found that the top four reasons for nursing home placement of a person with dementia were (1) care partner health problems. (2) the client's behavior was too difficult to manage. (3) the client

needed more care than the care partner could provide (with ADL's and incontinence), and (4) the care partner needed more assistance and felt unable to get help. Given that burden is a top reason that care partners fall ill, and burden is related to poor performance with activities of daily living and behaviors, burden may be positively impacted by OT. A directed program of identifying client skills, promoting ADL skills and leisure engagement, and educating care partners on how to continue promoting function of the client at the highest possible level would decrease burden and increase well-being.

Domains of OT practice:

This project fits under the domain engagement of occupation. The definition of engagement of occupation is “performance of occupations as the result of choice, motivation, and meaning within a supportive context and environment.” (AOTA, 2014, pg. 84). The specific occupations addressed are ADL, IADL and leisure skills. Several performance skills will be assessed and treated, including motor skills, process or cognitive skills, and social interaction skills. An environmental evaluation with the care partner or via telehealth will be conducted. In order to assess the client, an OT will complete an occupational profile and analyze occupational performance. A program will be developed designed to enhance the care partner’s ability to facilitate occupational performance at home. Essential to the process is establishing realistic goals with both the client and the care partner. Ensuring realistic goals will further contribute to the success of the intervention and quality of life markers.

What is causing/contributing to the problem?

In my clinic, several factors contribute to this problem. Dementia is often under diagnosed in early stages by the primary care physician (Alzheimer's Association, 2017). In the early stages, cognitive ability to learn routines may still be intact and treatment may be more effective. The care partner might then be better prepared as a decline in abilities occurs. Even if diagnosed, there is limited recognition in the local medical community regarding what OT can offer. Referrals are limited to evaluation of safety and the rate of referrals is not consistent with the number of those living with dementia.

Unfortunately, there is limited recognition among my OT co-workers about effective interventions to be used with clients with dementia and their care partners. Bennett, Shand, and Liddle (2011) found in a practice survey that OT practitioners reported being uncomfortable or unsure of treatment techniques for dementia. Having a protocol for evaluation and treatment will increase the comfort and skill level of the OT's that I work with in outpatient practice. Once more knowledgeable, an increase ability to advocate for OT services should follow.

Therefore, a lack of organized protocols contributes to the problem. Having a planned, yet client-centered intervention will allow the department to deliver services in a coordinated and consistent manner. Further, the use of evidence in the development of the intervention lends credibility when promoting our services. Once a treatment program is established and streamlined, research regarding effectiveness of the translation will be established. Evidence of effective treatment will contribute to reimbursement of services.

Reimbursement is a final challenge. Medicare and commercial insurers cover

therapy to restore lost skills or function and are increasingly requiring evidenced based practice. Payment will be linked to performance (Leland, Crum, Phipps, Roberts, & Gage, 2015). The burden will be on OT to demonstrate the value of therapy services and the effectiveness of dementia interventions, when restoring prior level of function is not the desired outcome. Excellent documentation will be required to establish measurable progress; goals will have to show the purpose behind care partner skills as a means to improve function in ADL's, increase quality of life, reduce caregiver burden, and save money with a decrease incidence of nursing home placement

How do I propose to address this problem?

My intervention will use current evidence to guide treatment protocols (Gitlin, Winter, Hodgson, & Hauck, 2010a; Gitlin, Winter, Hodgson, & Hauck, 2010b; Graff, Vernooij-Dassen, Thijssen, Dekker, Hoefnagels, & Rikkert, 2006). The framework of the intervention will include a thorough evaluation of the person with dementia using standardized existing measures. This will include an interview with the care partner and the client to identify priorities and desired occupations. Once the functional ability, the home environment, and priorities have been assessed, a written treatment plan will outline the activities to be practiced in the clinic and home to reach the goals. Simulations of activities will be used in the clinic or to teach the care partner how to successfully modify the task and environment to promote functional engagement of the care recipient at their highest level. Telehealth models will be used for patients that travel distance or have no transportation to the clinic. Telephone calls will serve to reinforce and support learning even for clients that attend therapy in the clinic.

Chapter Two Theoretical Foundation of the Problem and Intervention

In 2017, Alzheimer's dementia affected 5.5 million Americans with more than 15 million people acting as informal care partners (Alzheimer's Association, 2017). Care partners are susceptible to negative health consequences from the increased stress and burden caused by providing care. The Alzheimer's Association (2017) estimates a medical cost of 10.9 billion dollars related to the effects of the emotional and physical demands of caregiving. Care partner stress, burden and illness may lead to increased healthcare costs, including institutionalization of the person with dementia. Factors that lead to care partner stress, burden and illness include 1) barriers to healthcare related to the rural nature of New Hampshire, 2) decreased Primary Care Provider (PCP) knowledge of dementia signs and reluctance to diagnose 3) inadequate outpatient occupational therapy treatment programs for persons with dementia, and 4) decreased care partner knowledge and self-efficacy related to providing dementia care. Outpatient interventions aimed at increasing care partner self-efficacy and educating care partners on changing roles may decrease burden and improve quality of life thereby decreasing the likelihood of institutionalization and improving the health of both the care partner and the person with dementia. See Appendix A for a visual of this model.

The Problem

New Hampshire is a state that is considered nearly 50% rural (United States Census, 2016). Living in a rural area has been shown to limit access to a timely diagnosis of dementia (Forbes, Morgan, & Janzen 2006; Szmczynska, Innes, Mason, & Stark, 2011; Teel, 2004; Wiese, Williams, & Tappen, 2014). More importantly, the PCP often

does not provide an accurate and timely diagnosis of dementia. Mitchell, Meader, and Pentzek (2011) performed a meta-analysis and found that the PCP did not recognize cognitive impairment and when it was recognized, poorly documented those findings. In another study of 495 patients who were screened for dementia in a rural clinic, 198 had positive signs for dementia yet only 73 were recommended for a full workup (Boise et al., 2010). Teel (2004) identified that even if the PCP identifies dementia, there is a lack of services and specialists available for patients and care partners. Living in rural areas limits access to adequate services and the PCPs not recognizing, diagnosing, and documenting cognitive impairment limits access to timely treatment.

Occupational therapy (OT) is the ideal profession to address the skill deficits in daily activities both for the client with dementia and the care partner supporting that client as well as addressing the changing roles and responsibilities in the dyad (American Occupational Therapy Association, 2014). Nevertheless, there is a gap in the translation of the evidence demonstrating the effectiveness of interventions and the practice patterns of occupational therapists (Gitlin, Marx, Stanley, & Hodgson, 2015). Several studies looked at practice patterns of occupational therapists with regards to dementia care and several themes emerged (Bennett, Shand, & Liddle, 2011; Gately & Trudeau, 2017; McGrath & O'Callaghan, 2013; Swinson, Wenborn, Hynes, Orrell, Stansfeld, Rooks, & Ledgerd, 2016). The primary practice areas for dementia intervention by OT was either a facility, such as a hospital or skilled nursing facility, or in the home. There were no studies that included OT's working in outpatient facilities with people with dementia. The biggest barrier identified by most therapists was lack of time, with a second barrier

being lack of therapist knowledge and confidence to treat clients with dementia. Bennet et al. (2011) specifically pointed out that there was a lack of translating evidence of successful models of intervention into practice.

The practice patterns identifying occupational therapy as primarily happening in the context of the home or a hospital facility don't match where the clients are potentially located. Currently, there are approximately 46 million Americans over the age of 65 (Mather, 2016). In 2017, five million Americans are living with Alzheimer's disease (Alzheimer's Association, 2017). To receive homecare services with Medicare, one must be considered homebound, or unable to leave the home without great difficulty. Ornstein et al. (2015) did a cross sectional survey of all Medicare beneficiaries and found that there are approximately 2 million people considered mostly or completely homebound. 58% of people diagnosed with Alzheimer's dementia live in the community (Alzheimer's Association, 2017). Therefore, many of the people living with Alzheimer's are not likely considered homebound. Given the limited evidence that treatment was provided in the outpatient environment, a gap in current OT practice exists.

Moreover, due to limited access to services, care partners are often left with a lack of knowledge regarding the disease process and have poor self-efficacy for the tasks involved with caregiving. Semiatin and O'Connor (2012) demonstrated a positive relationship between self-efficacy and care partner's perceptions for positive aspects of caregiving. Therefore, poor self-efficacy could contribute to negative perceptions and potentially lead to care partner stress, burden and illness and possible institutionalization of the person with dementia. Several studies have identified care partner health and

burden as a primary reason for nursing home placement within the context of dementia (Buhr, Kuchibhatla & Clipp, 2006; Cepoiu-Martin, Tam-Tham, Weyerer, Konig, Brahler, & Reidel-Heller, 2010; Thoma-Lurken, Bleijlevens, Lexis, de Witte & Hamers, 2017; Toot, Swinson, Devine, Challis, & Orrell, 2017). In these studies, burden most closely relates to the care recipient's decline in ADL/IADL participation. Toot et al. (2017) specifically identified a lower sense of competence as a factor in caregiver burden.

Education on Alzheimer's dementia as a moderator of caregiver burden was not supported by evidence (deRoutrou et al., 2010; Sepe-Monti, Vanacore, Bartolli, Tognetti & Giubilei, 2016; Torp, Hanson, Hauge, Ulstein, & Magnusson, 2008). Understanding the disease process does not appear to significantly change care partner level of burden (de Labra et al., 2015; Jennings et al., 2015; Sepe-Monti et al., 2016). De Labra (2015) did identify support from a medical care professional correlated with lower measures of burden but overall education alone did not lower burden. There were limitations in the review of the evidence regarding education. The studies varied widely in the manner in which the education was delivered and ranged from individual sessions of 15 minutes (Seike et al., 2014) to manualized group delivery several weeks in nature (Sepe-Monti et al., 2016). Evaluation measures of burden were not consistent across studies and therefore hard to compare. Most of the education was manualized and not individualized or client centered, which would be more consistent with occupational therapy treatment standards (American Occupational Therapy Association, 2014).

Although education on the disease process alone does not appear to decrease or moderate burden, education on developing coping strategies and feelings of competence

(de Routrou et al., 2010; Jennings et al., 2015, Sepe-Monti et al., 2016), may lead to the development of self-efficacy. Self-efficacy is defined as the belief an individual has that he or she is capable of managing a situation or skill. Self-efficacy has been shown in the research to moderate burden and improve positive aspects of caregiving (Crellin, Orrell, McDermott, & Charlesworth, 2014; Semiatin & O'Conner, 2012).

Self-efficacy theory was proposed by Albert Bandura (1997) as a method to describe why people will attempt and persist at activities that are difficult or daunting. He felt that by building self-efficacy, people would be more likely to be motivated to participate and continue to persist at tasks perceived as difficult. Self-efficacy is different than self-confidence in that self-efficacy is task specific and can be developed by 1) modeling an observation of successful management of an activity, 2) successful participation in graded activities that lead to managing the activity independently and 3) feedback on performance from a trusted source (Bandura, 1997). In this manner, a person or care partner will develop the belief that he or she can manage specific activities as part of caring for a person with dementia. Occupational therapy is uniquely suited to improve care partner self-efficacy for ADL and IADL tasks as we are trained to examine the task, break it down into graded, manageable steps and build a client's ability to perform tasks with feedback and encouragement (American Occupational Therapy Association, 2014).

The Model of Human Occupation (MOHO) also guides the problem and the development of the intervention. MOHO looks at how a person engages in their everyday occupations and addresses volition, habituation and performance capacity (Kielhofner, 2009). Dementia disrupts all three areas not only for the person with dementia but for the

care partner. As the person with dementia experiences deficits in volition and difficulty with performance, the care partner needs to develop volition and take on new daily activities that are unfamiliar and require new performance abilities. Both the person with dementia and the care partner experience changes in roles, habits and expectations. This can cause stress and burden on the part of both participants in the caregiving/care recipient dyad.

MOHO and self-efficacy are intertwined concepts that promote performance at one's highest ability. An aspect of MOHO is being motivated to participate in occupations that contribute to a meaningful occupational identity, defined as the "cumulative sense of who they are and wish to become as occupational beings" (Kielhofner, 2009, p153). Volition and personal causation are related to the motivation to engage in occupations and develop occupational competence (Kielhofner, 2009). Self-efficacy theory posits that motivation arises from the sense of competence derived in mastering a task. People will persist in an activity previously perceived as daunting or difficult once self-efficacy is achieved (Bandura, 1997). The care partner that develops self-efficacy will have occupational competence for providing care. The role of caregiving will become part of the person's occupational identity and create satisfaction in that role.

Conclusion

People living with dementia and their care partners are a growing population that need access to quality healthcare. Rural locations, lack of a timely diagnosis by a PCP and limited access to adequate outpatient OT treatment may negatively affect the care

partner's ability to develop the skills to gain a sense of self-efficacy needed to provide care and limit burden. The care partner and the person with dementia need to adjust to changing occupational performance and roles. These elements can cause stress and burden, which may lead to increased illness, health care costs and possible institutionalization. The proposed intervention in this project considers the factors that limit access and treatment for care partners and people with dementia and develops an intervention designed to provide evidence-based care at an outpatient facility.

Current Evidence to Support the Intervention

Introduction

Occupational therapy (OT) supports engagement in meaningful and desired occupations at a person's highest level possible. Intervention is based on an assessment of client factors, performance skills and the context and environment within which a person exists (American Occupational Therapy Association, 2014). Alzheimer's disease is a progressive disorder with no known cure and a clear decline in functional ability to engage safely in activities of daily living (ADL) and instrumental activities of daily living (IADL; Alzheimer's Association 2017). Decline in ADL performance is a leading reason for nursing home placement by care partners (Buhr, Kutchibhatla, & Clipp, 2006), therefore, occupational therapy is an appropriate health profession to address this deficit in occupational engagement.

Despite quality evidence that occupational therapy interventions teaching care partners specific skills to support a person with dementia in participating in daily activities have significant positive impact (Dooley & Hinjosa, 2004; Gitlin, Winter,

Burke, Chernett, Dennis and Hauck, 2008; Gitlin, Winter, Hodgson, & Hauck, 2010a; Graf, Vernooij-Dassen, Thijssen, Dekker, Hoefnagels & OldeRikkert, 2006), the rate at which evidence based programs addressing occupations and activities of daily living are being translated into practice is alarmingly low (Gitlin, Marx, Stanley, & Hodgson, 2015). New Hampshire is a rural state where access to medical care is a challenge, further complicating translation of researched interventions into clinical settings. Telehealth, as an emerging field in medical intervention delivery, has demonstrated increased care partner self-efficacy and decreased levels of depression (Blom, Zarit, Groot Zwaaftink, Cuijpers & Pot, 2015; Finkel, Czaja, Schultz, Martinovich, Harris & Pettuto, 2007; Jackson, Roberts, Wu, Ford & Doyle, 2016; Steffen & Gant, 2015). Current evidence supports the potential efficacy of a combined face to face and telehealth-based outpatient program to increase care partner competence in engaging the care recipient in daily occupations.

Summary of the Evidence

There are three OT approaches to support care partners of people with dementia represented in current evidence: 1) methods designed to delay and preserve functional ability 2) methods teaching care partners specific skills to support the care recipient after a thorough evaluation and practice with their family member and 3) care partner education regarding general methods to manage a person with dementia in ADL tasks. A long term study that was designed specifically to measure whether OT intervention resulted in a delay of functional decline demonstrated indeterminate results (Callahan et al., 2017). Physical function was measured at baseline. The intervention group received

OT visits over a period of two years in the home with the education and visit guided by care partner and care recipient need. Treatment often focused on transfer training and mobility. There was no significant delay in functional decline for the group that received OT, yet the intervention group had less measurable decline than the control group. Unfortunately, the measures used to determine functional decline were related more to muscle function and included only one ADL checklist. Care partner satisfaction and competence was not measured in this study. This study suggests that prolonged OT intervention periods to delay functional decline are not effective in the dementia population.

Similarly, cognitive retraining or rehabilitation has not been shown to have any effect on improving ADL performance in the person with dementia (Garrido-Pedrosa, Sala, & Obradors, 2017). Compensatory or remedial cognitive strategies had mixed results on ADL performance. No evidence supports cognitive training tasks to support ADL performance. Garrido-Pedrosa et al. did find that cognitive stimulation, or the engagement in social activities or occupations that required conversation and problem solving had a positive significant effect on ADL. Therefore, it is likely that interventions that include a stimulation component, such as asking questions about past or current events, are more successful in improving ADL performance in people with dementia than compensatory or remedial cognitive strategies.

Two programs attempted to improve ADL performance and teach care partners how to better engage the person with dementia in daily occupations (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010a; Graff, Vernooij-Dassen, Thijssen, Dekker,

Hoefnagels, & OldeRikkert, 2006). In both programs, clients with dementia were assessed at home to determine a current functional level with a concurrent environmental evaluation. Community Occupational Therapy in Dementia (COTiD) by Graff et al. (2006) and Care of Persons with dementia in their Environment (COPE) by Gitlin et al. (2010) teach the care partner how to simplify tasks, modify the environment and communicate more effectively with the person with dementia. Graff et al. included care partner self-care as a component. COTiD had more significant findings for increasing ADL engagement than COPE, however, enhanced care partner well-being was reported in both programs.

Interventions that addressed care partner involvement and training had more significant impact on not only ADL engagement by the person with dementia but also care partner satisfaction and well-being. Along with a decline in ADL, feeling overwhelmed by the care required, or caregiver burnout, is another leading reason for nursing home placement, (Buhr et al., 2006). Increased sense of self-efficacy for caregiving is associated with lowers levels of burden and depression (Gallagher et al., 2011). Both the COPE and COTiD programs focus on teaching the care partner how to engage the person with dementia at their current functional level. The care partner is taught how to change the environment—for example, reduce distraction and clutter—to encourage improved performance. Simplifying a task to suit the cognitive and physical skills of the person with dementia is practiced with the OT. COPE (Gitlin et al., 2010a) provides care partners a “prescription” for each identified problem area. COTiD (Graff, et al., 2006) uses the Canadian Occupational Performance Measure (COPM) to identify

priority areas to address. Similar to COPE, in COTiD, methods to change the task and environment are taught and practiced with the care partner. Both studies demonstrated significant changes in care partner well-being and both studies use the principles of developing self-efficacy through guided practice and mastery.

Dosing may be a factor in success of a program. Both interventions use ten visits, COTiD over five weeks and COPE over 16 weeks. Voight-Radloff et al. (2001) performed a replication study of the COTiD in Germany. They compared the standard version of the 10 visits of the COTiD with one training session of education considered standard care. Both the groups had positive changes but neither group showed significant positive changes. Interestingly, the German study used different ADL outcome measures which may have affected the significance of the findings. In the United States, Dooley and Hinojosa (2004) designed a brief two visit program that was client-centered and focused on care partner skills. In this intervention, the OT evaluated the current level of skills of the person with dementia and wrote a plan of recommendations for the care partner to modify the environment, modify the task or seek community resources. This plan was reviewed with the care partner at a second visit but the skills were not practiced. At a one-month follow-up, care partners were reporting a significant reduction in burden and an increased frequency of participation from the care recipient in ADL activities. Both the study by Voight-Radloff et al. (2011) and Dooley and Hinojosa (2004) had positive results with brief interventions.

Despite some studies demonstrating success with brief interventions, a one-visit educational intervention by DiZazzo-Miller, Winston, Winkler, and Donovan (2017) had

less positive results. In this intervention, care partners were taught dementia management techniques, including managing communication, feeding and eating, toileting and transferring, and dressing, bathing, grooming, in a group setting. The care partners practiced skills with each other during the course of training but the care recipient's level of function was not evaluated and the skills were not personalized to the needs and problems experienced by the care partner. There was no measurable difference between control and intervention for care partner confidence or on measures of burden, depression and quality of life. The only significant difference between groups was related to care partner knowledge.

Resources for Enhancing All Caregivers Health (REACH) program (Easom, Alston, & Coleman, 2013; Nichols, Martindale-Adams, Burns, Zuber, & Graney, 2016) is another model of intervention that demonstrated positive impact on caregiver self-efficacy and burden. While not OT based, the components of the intervention are within the scope of OT practice: education, support and skill building to address care partner's ability to manage stress and the care recipient's negative behaviors. It was designed as 12 individual home visits and five telephone support group interactions. The specific intervention with the care partner was based on a care partner risk inventory with education directed towards personalized risks. This intervention does not include an evaluation of the care recipient's cognition or level of function. Easom et al. (2013) found significant decrease in burden and depression with no increase in self-efficacy. Regarding dosing, the Veteran's Administration was able to modify the program to four visits with the same significant reduction in burden and depression (Nichols et al., 2016).

Other group and coaching models had some support in the literature, yet due to poor study quality, conclusions based on this research is difficult. Chenoweth, Stein-Parbury, White, McNeil, Jeon, & Zaratan (2016) evaluated a coaching program to improve self-efficacy to reduce burden and depression. Care partners were coached through eight learning modules in developing and practicing self-determined goals, caring for themselves, reflecting on achievements and adapting to the carer role. Some carers participated in a group and others individually, depending on preference, not randomization into groups. The study found positive but not significant results. The methods used in this study were somewhat unclear and not rigorous, making a conclusion difficult. Coaching appears to have potential merit as part of an intervention to develop self-efficacy.

Rosney, Noe and Horvath (2017) describe a scripted, structured group program that is widely available for care partners. The Powerful Tools for Caregiving (PTC) is a train the trainer program, meaning trainers are care partners that have completed the program and are now certified to lead groups. The curriculum is a series of 2.5 hour classes educating care partners in stress reduction, communicating needs, dealing with difficult feelings, making tough decisions and accessing community resources. The authors found significant positive changes on the measures used, however the measures used were behavior counts done by care partners and single item Likert scales. They did not use a standardized reliable or valid measure on which to base conclusions. The authors suggest positive changes in self-efficacy are present but the statement is based on comparison with other research and not measured as part of this study. This program

was widely accepted by care partners, with over 70,000 having attended (Rosney et al. 2017) and its wide adoption suggests it should be considered when designing an intervention to reduce caregiver burden. Nevertheless, assuming the program contributed to self-efficacy as a moderator of caregiver burden must be regarded conservatively.

Both the REACH program and PTC program have been translated into telehealth programs (Finkel, Czaja, Schultz, Martinovich, Harris & Pezzuto, 2007; Serwe, Hersch, Pickens, & Pancheri, 2017). Serwe et al. (2017) interviewed care partners that identified leaving the home as a barrier to receiving services after they participated in a synchronous, internet-based group meeting for PTC. The findings of this qualitative study focused on perceptions of the telehealth-based intervention. The authors concluded that the care partners felt they had valuable learning during the PTC program and that the telehealth nature of the group meeting was acceptable. In the REACH telehealth application, participants received one face to face visit for education on how to use the telephone provided. Using a telephone with a screen, care partners participated in eight individual learning modules and six support group modules with other care partners. While the effect of the intervention did not reach a significant level, it was accepted by the care partners (Finkel et al., 2007).

Given that care partners cite lack of time (Serwe et al., 2017) and that New Hampshire is a rural state with decreased access to services, the acceptability and accessibility of telehealth has great potential for increasing the reach of OT interventions. Malinowsky, Nygard, & Kottorp (2014) found that using e-health methods was both acceptable and accessible to older adults. They developed a screening tool and found that

adults with dementia were willing to use technology. It appears that having a person to person live element, whether video, phone or in person, along with technology, increases participation. Interventions without any live component are less successful. Blom, Zarit, Groot, Zwaafink, Cuijpers, and Pot (2015) analyzed a program called Mastery over Dementia (MoD) in a randomized control trial with 251 participants. The curriculum was eight online modules with coach feedback by email after the completion of each lesson, with no video, telephone or in person contact. While the authors found a significant effect on reduction of depression and anxiety, there was a high dropout rate of 50%. Finally, a systematic review by Jackson, Roberts, Wu, Ford, and Doyle (2016) examining the effect of telehealth interventions on carers of persons with dementia concluded that telehealth programs, whether by telephone, internet or combined, were able to achieve significant effects on increasing self-efficacy and decreasing burden and depression.

Successful interventions that take place in person included telehealth components using more face to face than telehealth visits. It may be appropriate to alter the ratio by increasing the telehealth visits and decreasing the face to face visits within the scope of the intervention. The REACH program described by Easom et al. (2013) and Nichols et al. (2014) included telephone support as needed. Gitlin et al. (2010a) include one telephone follow-up by an OT and one by an advanced practice nurse. Both studies had positive findings for decreasing burden and increasing well-being of the care partner. It is possible that more of the in person visits could occur using technology to reach clients with limited transportation in rural areas. Telehealth, incorporated into traditional service delivery methods, is outlined in the literature and strong studies support efficacy of mixed

intervention methods.

Conclusion

There is strong evidence that OT interventions increase the engagement of a person with dementia in ADL and meaningful occupations if the care partner is included and taught specific caregiving skills. The strongest outcomes were programs that not only included the care partner, but evaluated the person with dementia's current abilities, considered the areas of concern most pressing to the care partner and care recipient and provided recommendations specific to their situation. Less personal programs increased knowledge but did not increase engagement, care partner skills, self-efficacy or reduce burden. When considering burden, programs that practiced skills even when not directed towards engaging the care recipient, had the most significant effects on self-efficacy. Bandura (1997) proposes that practice of skills with feedback from a professional is key to the development of self-efficacy. Interventions that did not provide that training, practice, and feedback had less or no significant results. The ideal dosing of the intervention is not defined in the literature. Significant benefit was achieved in as few as two visits (Dooley & Hinojosa, 2004) and as many as 10-12 visits (Gitlin et al., 2010a; Graff et al., 2006). Further, visits can occur in a telehealth format and be accepted and effective. In a rural state, an intervention that combines in person and telehealth means will have farther reach and provide quality client-centered care.

Chapter Three: Description of the Intervention

Overview

This intervention is designed to provide a care partner with the tools to facilitate and enhance the ability of a person with dementia to participate in occupations and to decrease care partner burden. It consists of six visits with a clinic based initial evaluation. The following five visits have the flexibility of being clinic or telehealth depending on reimbursement, client location and transportation, and available technology. After developing recommendations based on evaluation findings, the occupational therapist will demonstrate facilitation of the task for the care partner with the client. Then the care partner will perform a return demonstration of the techniques with occupational therapist feedback. The care partner will then be encouraged at home to practice the recommended techniques to enhance the engagement of the client in targeted occupations. Enhanced wellness and quality of life for both the client and care partner is an expected outcome.

Participant

A person diagnosed with dementia, by a primary care or specialist, who is experiencing a functional deficit in basic or instrumental activities of daily living (ADL or IADL). The client must have an involved care partner that participates in care a minimum of 5 days per week for some part of the day, ideally two or more hours at a time. The care partner must attend all appointments and be willing to fully participate in intervention with carryover in the home.

Intervention delivered by

An occupational therapist (OT) trained in using the evaluation tools and in developing the written plan. Subsequently the OT or trained occupational therapy assistant (OTA) will practice the skills and suggestions from the written plan with the care partner and care recipient.

Location where intervention delivered

Hospital based outpatient clinic with a telehealth component to address limited transportation or great distance to travel. Format is flexible enough to be delivered in multiple settings depending on the circumstances.

Desired outcome

Person with dementia: increased engagement with desired occupations. Care partner: increased QoL, decreased burden and increased self-efficacy with managing the tasks of caregiving by learning to modify tasks and the environment.

Intervention description

1. Referral from primary care provider (PCP) or specialist for OT evaluation and treatment
2. First visit: Evaluation (using Graff et al., 2006 description of evaluation):
 - a. Establish treatment goals and priorities using Canadian Occupation Performance Measure (COPM; Law et al., 2014)—interview with client and care partner to gain perspective on current strengths and limitations, past performance and desired occupations (Graff et al. 2006). Use the interview to determine current status for bathing/dressing/grooming, meal

prep, driving, bill paying, laundry and other instrumental activities of daily living. Determine current amount of supervision and how much time is spent alone. Try to limit to top three or four desired occupations to focus treatment for effectiveness (Gitlin, Winter, Burke, Chernett, Dennis and Hauck, 2008; Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010a).

- b. Evaluate current cognitive and physical skills of person with dementia to guide intervention
 - i. Allen Cognitive Level Screen (ACLS; Allen, C. 1996): this tool gives a score that correlates with an expected ability to learn and participate. For example, if a client scores 4.2 or greater, there is a higher likelihood of potential learning of new routines and carryover. On the other hand, if the client scores under 4.0, there is likely limited ability to participate without structure and guidance.
 - ii. Montreal Cognitive Assessment (MoCA) if not done by referring provider: The MoCA is a validated tool (Lam et al., 2013) that provides a quick screen of several domains: attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculations, and orientation. It can provide information regarding areas to evaluate further.

- iii. Executive Function Performance Test (EFPT; Baum et al. 2008): a functional test to provide an opportunity to look at functional problem solving and performance. People can do better or worse on paper/pencil tasks than they do in functional situations. The EFPT uses cooking, medication management, and bill paying to assess executive function skills within daily tasks.
 - iv. Home evaluation if care partner brought video of the home, otherwise done by interview. Request care partner bring in video of the home at second visit. This portion of the evaluation will look for possible safety hazards, visual clutter, and other areas to modify as well as the strengths of the environment to refer to in the clinic while practicing skills.
- c. Have care partners complete the outcome tools while the person with dementia is undergoing testing:
- i. The Revised Scale for Caregiver Self-Efficacy (Steffen, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002). This tool was developed specifically to measure the self-efficacy for meeting the needs of a care recipient with dementia including managing negative behaviors and obtaining services. It was shown by the authors to have construct validity and good test-retest reliability.

- ii. Zarit Burden Interview is a 30 item interview to measure burden (Zarit, Reever, and Back-Peterson, 1980) that has demonstrated reliability and validity (Herbert, Bravo, and Preville, 2000). A 12 question short version has been developed, and is a valid and reliable tool to measure burden (Bedard et al., 2001) and the shorter time taken is a benefit in the clinic.
 - iii. CarerQoL (Hoefman et al., 2011)—a Likert scale designed to measure quality of life for a care partner. Includes a happiness Likert scale. Clinical utility not established. Few measures of positive care partner attributes—satisfaction, self-efficacy or QoL have the psychometric properties fully evaluated (Stansfeld et al., 2017).
- 3. Occupational Therapist interprets the evaluation data and develops written recommendations. Recommendations will fall into five categories: modification of the task, modification of the environment, communication, coping with negative behavior and stress management. See appendix B for samples of possible recommendations for each category. The therapist can use the preformatted samples to copy and paste general recommendations as long as they are then personalized for the client’s and care partner’s situation. This will streamline documentation while staying client-centered.
- 4. Follow up Visits
 - a. Current evidence supports a series of 10-12 home visits over a period that

ranges from five weeks to six months (Graff et al. 2006; Gitlin et al. 2010a and 2010b). However, Dooley and Hinojosa (2004) found that two visits can be effective for increasing quality of life measures. The rationale of six visits is a balance of thorough evaluation and time to practice with the occupational therapist to facilitate self-efficacy at home. Telehealth visits every other visit could enhance treatment by allowing the care partner to practice in the home with guidance. Establishing the expected time frame for visits will encourage being goal focused in treatment and provide a framework for the intervention. The written plan should outline a plan for progression over six visits to address the priority areas. For example, the written plan should outline which goals will be addressed at each visit, keeping in mind general strategies may be applicable for all the goals.

- b. Meet weekly or every other week for an hour, depending on care partner learning, understanding of the material and ability to reach clinic. Use telehealth means to meet when this technology is reimbursable.
- c. Each visit would follow the same structure: 1) Review of the prior week(s) to identify successes and challenges; 2) Problem solve challenges at home that occurred over previous time since the last session; 3) Practice the occupation to be addressed that session which includes modeling of the strategies by the OT, practice by the care partner mimicking the modeling, followed by feedback on performance by the OT; and 4) Identify a plan for carryover at the home over the next week(s). This cycle is based on

principles of building self-efficacy (Bandura, 1997). Success in facilitating the desired occupation will enhance feelings of self-efficacy. Each visit needs to be progressive and move through the occupations identified at the evaluation.

- i. Specific suggestions will include the amount and type of cueing, breaking the task down into simpler steps, doing more complicated portions and allowing the person with dementia success in participation, and environment modifications. Please see appendix B for samples of the checklists that contain the following types of strategies:

1. Cueing: limiting verbal information that may be confusing. Using clear directive terms, using tactile cues instead of verbal cues, pausing to allow time to process verbal cues. Avoid confrontational language and use stress management techniques (also given as educational handouts) such as counting to ten or taking deep breaths to manage care partner frustration.
2. Task modification: labeling items in bathroom needed to complete a task. Laying out clothes in correct sequence to don. Placing needed tools for a task in plain view on table. If the person with dementia can use the stove, having ingredients out already and supervising the stove use. If

not, giving the care recipient tasks to assist such as mixing in a bowl, sorting dishes, setting the table. Other household tasks such as folding laundry or vacuuming, assisting with cueing for thoroughness. Doing leisure activities such as puzzles or computer use together to allow the recipient to participate in a guided, supported fashion. Awareness of social situations-participating in selected social engagements that are appropriate for the skill set of the person with dementia, for example, with familiar people or in a quiet restaurant.

3. Environment modifications: limit distractions by reducing extra noise when concentrating. Using music to enhance calmness. Brightly lit work areas. Limiting clutter and visual confusion. Keeping dangerous objects out of sight or reach (such as knives).
- d. Educate care partner on resources available and refer to social worker if needed to apply for funds, grants or pursue respite available from community agencies.
- e. Phone calls in between visits, especially if every other week. Phone calls need to be limited to problem solving specific situations (not counselling sessions).

- f. Telehealth visits would follow same format as an in-person visit, on screen through Skype or other video call service.
- g. The last visit must include a repeat of the COPM, QoL measures, the Self-Efficacy for Caregiving scale and the Zarit Burden Scale.

Challenges:

1. Referral base: will need to be given time and resources to market the program in my current clinic environment.
2. Reimbursement for telehealth: no standardized method to bill insurance, particularly Medicare. Most telehealth modules are in the Veteran's Administration or done for research populations. Limited information on billing in real clinic settings at this time.
3. Ensuring that the home environment is adequately addressed through video or telehealth means, especially if telehealth is not an option. Look into the feasibility of one in home visit or providing the care partner with resources to make the video if the technology is not available.

Chapter Four: Program Evaluation

Title of program evaluation

Feasibility and efficacy of an intervention to improve self-efficacy of informal dementia care partners to increase engagement of care recipient in ADL's and IADL's in the community.

Overall Vision

Over 5 million Americans have Alzheimer's disease and 15 million Americans are providing informal care for them (Alzheimer's Association, 2017), yet only a few translational programs based on current evidence exist in the literature (Gitlin, Marx, Stanley & Hodgson, 2015). Gitlin et al. (2015) identify over 200 proven interventions for dementia but only 6 "have been submitted to a translational process resulting in publication" (p. 213). Using self-efficacy theory (Bandura, 1997) and Model of Human Occupation (Kielhofner, 2009), this doctoral project will be an outpatient translation of evidence-based home therapy interventions using a client centered approach to teach specific skills to a care partner (Fortinsky et al., 2016; Graff et al., 2007). Self-efficacy is shown to moderate burden and increase the positive aspects of caregiving (Crellin, Orrell, McDermott, & Charlesworth, 2014; Semiatin & O'Conner, 2012). After a thorough evaluation to determine the client's current cognitive and physical abilities, a tool such as the Canadian Occupational Performance Measure (COPM; Law et al., 2014) will assist in developing personalized, client centered goals. Three client-care partner goals will be the focus of individualized treatment, teaching specific skills to the care partner for modifying the task and the environment to support performance of the care recipient.

Three goals will be the focus initially to limit the burden of learning and avoid overwhelming the care partner. Introduction of the activities would follow a progression designed to promote self-efficacy in performing the task at home with the care recipient. Care partner and client dyads will be recruited from local primary care practices and the services would be provided in a hospital based outpatient clinic or via telehealth as appropriate.

The program evaluation has a dual purpose: to ensure the content is appropriate and engaging, and the program is effective in achieving desired outcomes. Information collected from the occupational therapists (OTs) performing the intervention and from the participants will help shape the approach. The data will be gathered as part of a formative evaluation to determine content, method of delivery and dosing of the intervention needed to achieve the desired goals. Outcome or summative data will also be collected relative to increasing engagement of the person with dementia and decreasing burden, increasing Quality of Life (QoL) and increasing self-efficacy for the care partner. Outcomes must be reached in a fiscally responsible way for reimbursement and funding. Costs that are not reimbursable, such as training for OTs to provide the service, the materials and supplies for evaluation, time for data management, and marketing expenses need to be identified and included.

The stakeholders most interested in this information would be: 1) the care partners that would benefit from participating, 2) the medical providers that would refer clients to the program, 3) the OT's providing the intervention and 4) the administrators that make financial decisions regarding programs to support for development within the facility.

Care partners and medical providers want to know that a program will achieve its promised results and be worth the investment of time and energy required to participate in the program. The OTs need to see that if they provide the intervention in the intended manner, it will have positive results. Finally, the administrators need to have a realistic view on the cost of the program so that appropriate funding can be secured if Medicare reimbursement is not sufficient. These are the critical stakeholders initially identified as targets to receive the evaluation results.

Evaluability Assessment

Some of the stakeholders will be vital on the evaluability assessment team. The team would ideally meet as a group at least once to have multiple points of view represented in an interactive way. Prior to a group meeting, the program logic model and plan will be available for review and comment. In this way, the program can undergo any obvious refinement before stakeholders are brought together. Stakeholders will have different levels of engagement with the program. The OTs on the evaluation team can problem solve barriers to training and uniform delivery of content. Once they understand the purpose and scope of the project, they will have input on the content and delivery within the context of the clinic resources and environment. Negotiating the manner in which the intervention is delivered regarding environment, training, scope and activities will increase compliance with the format and documentation to create the reproducibility. Having a social worker as a member of the team can identify social barriers to participation and provide insight into overcoming transportation and financial issues. A medical provider with expertise on dementia and aging may have input on outreach to

other physicians and care providers, as well as ensure client inclusion criteria meet medical standards for diagnosis and treatment. Finally, a team member familiar with coding and reimbursement issues can ensure documentation and billing is appropriate and meets medical necessity. Subsequent evaluability team members may include care partners that have completed the pilot intervention to further refine the program and improve the success.

Core Purpose

The core purpose of the evaluation is both causative and descriptive. The descriptive aspects include identifying costs, potential reimbursement, the numbers of clients, the number of potential clients and the satisfaction of the stakeholders, including participants. A causative evaluation will be used to determine the effectiveness of the intervention. In other words, does the intervention result in increased engagement, increased self-efficacy, increased QoL and decreased burden? If it does not, then the intervention needs to be modified and reformulated based on the data.

Scope

Client inclusion criteria for the intervention will include a diagnosis of dementia, English speaking, having a regular, informal care partner that provides at least four hours of assistance weekly, and living in the community yet not being considered homebound (not qualifying for visiting nurse services). The services will take place in a hospital based outpatient clinic that provides transportation for local residents. The only limit to number of clients is the scheduling constraints for the OT's providing the service.

Realistically six to eight clients completing the intervention in nine months will give

preliminary data on the effectiveness of the program and provide sufficient numbers for a focus group. The intervention is designed to span three to six months between active intervention and telehealth follow-up by phone. Therefore, an evaluation period lasting at least one year would be necessary to gather data on completed cases and conduct a focus group. It may take two years, depending on the amount of referrals. The evaluation process needs to be active from the start to look at the referral and marketing process and startup costs and training.

Evaluation Questions

The questions that need to be answered are as follows:

1. What are the costs—supplies, space, training for the intervention OT's?
(Administrative)
2. Can the OT's easily administer the evaluation tools and the intervention in a timely and effective manner? (Interventionist and Administrative)
3. Is the dosing/number of visits effective and reimbursed by insurance?
(Interventionist and Administrative)
4. Does the intervention have the intended outcome (increased self-efficacy, decreased burden, and increased QoL for care partner, increased participation with ADL's for the person with dementia)? (Interventionist, Medical Provider, Clients)
5. Are the stakeholders (OT, care partners, clients & providers) satisfied with the outcomes and content of the intervention? Are referrals increasing? (Everyone)

Proposed Research Design

A quasi-experimental design with a pre and post-test analysis of one group of subjects is the method of measuring the outcome of the intervention. In the initial stages, there will not be enough test subjects to have a control group, even for delayed treatment. A mixed methods design will evaluate the program in a summative and formative manner. A summative evaluation will measure program success and be used to promote the program for both referrals and funding. Quantitative data will drive much of the summative evaluation: 1) cost vs reimbursement, 2) quantitative measures of change for the client and care partner pre and post intervention, 3) number of goals met vs unmet 4) attrition or dropout rates, 5) referral rates, 6) Likert scales to measure client satisfaction with the intervention.

Both quantitative and qualitative data will drive the formative evaluation. Quantitative data will show if the intervention works based on test scores. Qualitative data will speak to the experience of the program and provide valuable information on the perceptions of the education and training. Qualitative data would be collected through an exit survey at discharge and focus groups. The interview would consist of questions designed to understand the experience of the intervention so that the content and delivery methods could be evaluated. The qualitative data can be linked back to the quantitative data to examine why goals were not met or improvements were not seen. In this way, the content can be improved to better meet the needs of the consumer.

Data Gathering

The quantitative data will primarily be gathered through the test data related to the intervention and collected demographic information from the patient and care partner. Demographic data will include age, marital status, hours of caregiving provided, whether care partner lives with care recipient, educational level, race, medical conditions and medications, and years since diagnosis. This is in addition to data collected through reliable and valid assessment tools as part of the evaluation. Cognitive measures will include the Allen Cognitive Level (ACL) and the Montreal Cognitive Assessment (MoCA). Functional skills will be assessed through the Executive Function Performance Test (EFPT). Information regarding activities of daily living and leisure skills will be collected with the Canadian Occupational Performance Measure (COPM). The COPM is designed to create client centered goals, identifying those skills and activities that matter most to the client. Care partner measures of self-efficacy and burden include the Revised Scale for Caregiver self-efficacy (Steffen, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002), the Short Form Zarit Burden Interview for caregivers (Bedard et al., 2001), and the Carer QoL (Stansfeld et al., 2017). The COPM, and the care partner measures are the pre and posttest outcome measures. Further, upon discharge a survey created by the program director to examine the qualitative experience of the program will be conducted with the care partner. Focus groups will occur after there are sufficient participants, (i.e. 6-8), to hold the group. That group will comprise of a semi-structured interview with guiding questions to solicit information regarding the experience of participating in the program, the effectiveness of the intervention and the long term

impact. Questions will echo themes derived from the discharge surveys. Groups will be audio recorded and the program director will be responsible for transcribing those tapes. A graduate student from an OT program at Boston University, University of New Hampshire or Massachusetts College of Pharmacy and Health Sciences may be recruited to assist with research functions such as transcribing as part of an independent study. Recordings will be destroyed after transcription.

Data Management

Certain demographic data is collected in the chart as part of regular care. Additional data will be collected by the OT providing the intervention to control the data and ensure full collection of needed information. All data collected on paper will be saved in a file in a locked cabinet. The hospital uses Cederon electronic documentation with reports stored on a central server. The charting is merged in Soarian where the patient's medical record for any care in the Wentworth-Douglass system is stored. Data is password protected and access is granted through information services. All occupational therapy data will be recorded in one episode of care including evaluation findings, goals, treatment notes and discharge summaries. The point of input is the therapist's laptop but the data is stored on a central server that is encrypted for privacy and protection. Additional data that should not be part of the medical record, such as care partner evaluations and surveys, will be kept in a separate electronic file coded to preserve anonymity and paper copies will be secured in a locked file only accessible by study personnel. The program director, who is the lead investigator, will extract all data needed from the medical records for analysis with the assistance of an OT student if

available. Such electronic data will be on a laptop that is kept secure and backed up to the central database on the secure server at the hospital.

Data Analysis and Reporting

The demographic data will be collected and summarized in a descriptive format. This includes the average and standard deviation for each data point such as age, marital status, hours of caregiving, income and years of education with percentages for gender, ethnicity, relationship of care partner and other data more appropriately described in that format. Pre and post test scores will be analyzed for statistically significant changes at discharge and six months' post discharge. Care partner measures of self-efficacy, QoL, and burden are the scores of most interest at the six month follow up, indicating success of the intervention over time. A statistical program such as SPSS will be used to analyze the data, with the program director and research assistant inputting numerical data to ensure accuracy, privacy and security.

Number of visits attended and progress on goals identified by the COPM will provide both summative and formative data. Identifying the correct dosing of the program to be effective yet cost conscious is a major consideration for the program evaluation. Looking at these two data points will give valuable information regarding goal attainment and the number of visits needed to attain goals. Future program implementation can be guided by this information.

The program director and research assistant will manually analyze qualitative data. Using Likert scales allow the surveys to be tallied and converted into charts or graphs using Excel. Open ended questions on the survey, transcribed and examined for

themes, will provide structure for the focus group. Focus groups of 6-8 people will be conducted by the program director using a semi-structured interview approach. The transcripts of focus group audio recordings will be uploaded into NVivo software and then analyzed for themes until no further themes emerge.

Two reports will be generated, an executive summary and a more comprehensive technical report. The executive summary will have a clinical bottom line with direct information on effectiveness and recommendations or suggestions to be used for administrative, medical and layperson stakeholders. The technical report will be directed towards clinicians and academic purposes for either publication or more comprehensive refinement of the program. The data will be fully described and the qualitative themes will be outlined. In this way, the needs of all stakeholders and the success of the program are addressed.

Chapter Five: Funding Plan

Description of the program

Alzheimer's disease is a growing condition in the United States (US) with five million people diagnosed as of 2017. Eighteen million Americans are providing informal care to those diagnosed, often with limited training or preparation (Alzheimer's Association, 2017). The Alzheimer's Association (2017) estimates this will lead to billions of dollars in health care costs treating care partner illness and injury, much of it related to stress and burden. *Improving the Care Partner Experience: An Occupational Therapy Intervention for People with Dementia* is a program designed to educate and train a care partner in skills to promote functional engagement for their care recipient. Through a careful evaluation of current performance skills and desired occupations of both the care partner and the person with dementia, a comprehensive treatment plan is developed and implemented through a series of training sessions. The care partner is given a written plan and self-efficacy executing the plan is developed with the occupational therapist's guidance. Treatment sessions could take place in the telehealth environment, as that market grows. As care partner self-efficacy increases, they will likely experience less burden and stress and the person with dementia will stay engaged in meaningful occupation which is the goal of the intervention.

There will be expenses associated with implementing this program. This chapter will outline the expenses and revenue expected for implementation year one and continuation year two. This includes existing resources and needed supplies, personnel

and equipment. Revenue and grant opportunities are funding sources. An explanation of these areas is included.

Resources and Expenses

Available Local Resources

The hospital that I work for has resources that support the development of this program. These include existing clinic space, administrative support for scheduling and billing support, the computers and documentation systems to document the intervention and the personnel to carry out the intervention. Microsoft Office is available for creating the template for client education and Excel for tracking outcomes. Other resources provided by the facility would be supplies for printing marketing and educational materials. There is a marketing and publicity office that could assist with increasing public awareness of the program. The outcome measures being used, the Zarit Burden Interview, the Revised Scale of Caregiver Self-Efficacy, the Carer QoL, the MoCA and the Executive Function Performance Test (EFPT) do not have licensing fees or forms that require purchase.

Needed Resources and Expenses

Nevertheless, there are still personnel costs and supplies that need to be accounted for. There are supplies that need to be purchased and time for marketing and training. Supplies include the Canadian Occupational Performance Measure (COPM), a current Allen Cognitive Level Screen (ACLS) and the items needed for the EFPT. The needed supplies include the COPM with online access; the e-manual is \$27.47 and online access is \$10 per therapist, or \$30 with a per form fee of \$.15. One hundred forms will be

sufficient for \$15. The ACLS is \$150.00 for the leather lace tool and the manual. The EFPT includes a number of household items including a small pot, spoon, oatmeal, measuring cups, salt/pepper and a small assortment of distractor items. These items, with a bin to hold them, can be purchased for approximately \$100.

Therapist time for marketing and training is a larger expense. Three employees will be involved in training and implementing the program. The trainer will educate two co-workers in performing all components of the intervention including the evaluation tools, the outcome tools and the structure of the intervention. The intervention is designed to be flexible with the activities performed to keep it client centered yet be structured in delivery to develop self-efficacy and be focused on the individual outcomes. To be able to compare outcomes across participants and to evaluate effectiveness, the intervention needs to be delivered in a consistent manner. Staff training should take approximately a total of eight hours, with the potential for refresher meetings after that as needed. The average therapist salary is approximately \$39 per hour at my facility. The cost of training would be \$936.00 (three therapists at eight hours).

Marketing would include developing promotional materials for the marketing department to produce and time speaking with physicians at their offices to promote the program. Developing the information for a rack card will take approximately four hours with initial content and revision. Getting time to speak at physician offices is difficult but it is reasonable to expect eight hours of time with making contacts, traveling and presenting over the course of the first year. Other places to speak would include a community lecture, the local Memory Café and at care partner support groups. The total

time formally spent on marketing is therefore 14-20 hours at an approximate cost of \$546-\$780.

Year two should have fewer costs as the supplies will be available. Once initial marketing has taken place, word of mouth and physician knowledge will increase referrals to the program. Table 5:1 outlines the expenses.

Table 5:1 Expenses Year One and Two

Expense	Year One	Year Two
Supplies	ACLS: \$150.00 COPM: \$72.47 EFPT: \$100.00	N/A, using original forms still
Clinic space: table, lights, heat, etc.	Provided by facility	Provided by facility
Computers for documentation and patient education handout	Provided by facility	Provided by facility
Microsoft Office	Provided by facility	Provided by facility
Administrative Support	Provided by facility (regular job duties)	Provided by facility (regular job duties)
Paper, phones, office supplies	Provided by facility	Provided by facility
Therapist time for training	\$936.00 (three therapists at eight hours each)	\$468 (refresher course and revision as needed, four hours for three therapists)
Dissemination Plan	\$835.00	\$2015.00 (National conference presentation, not a facility cost)
Total	\$2143.47	\$2483.00 total, \$468.00 for facility

Funding

This intervention is billable to Medicare and other private insurers. Each session should last approximately one hour with a course of treatment lasting six visits. At current rates for Medicare, a billed unit of therapeutic activity is reimbursed at \$42.55 per

15-minute unit. Therefore, a treatment session would net approximately \$170.20; over a course of six visits, the course of treatment would generate \$1021.20 dollars. Given that the hospital has overhead expenses, and therapist time would cost \$274.00, a profit of \$230-\$300 is likely realized from each course of treatment. The program is designed to minimize paperwork time for the therapist with formatted handouts that have basic information with the ability to customize the information. This would lend itself to the overall ability of the OT to meet productivity requirements within the structure of the intervention. Over time, the hospital would see a profit from starting this program.

Year one would focus on the training, startup and marketing of the program. Once the program is established and evaluated by stakeholders, research and growth opportunities could be explored. Research would not be supported financially by the facility, however the facility would accept research grants to fund the time of the principle investigator (PI) and administrative support needed.

To defray startup costs and to fund research opportunities, several possible funding sources have been identified. Table 5:2 outlines several grant and funding sources available. The resources identified are either related to the facility, to Alzheimer's and care partner research or to occupational therapy research.

Table 5: 2 Grants and Funding resources available

<p>Wentworth-Douglass Hospital Foundation</p>	<p>The Foundation was created to fund community health initiatives and provide community members with access to quality health care. They accept requests for donations from internal and external candidate. Requests to this organization would be to fund community lecture series or support group events supporting this program. They would also fund supply requests that are not routine budget items. Awards are nominal and subject to available monies and priorities of the Foundation. Typical grants range from \$100 to \$1000.</p>
<p>National Institutes of Health Grant</p>	<p>Research on Informal and Formal Caregiving for Alzheimer’s Disease (Clinical Trial Optional). This Funding Opportunity Announcement (FOA) invites applications for basic and translational research on caregiving for individuals with Alzheimer’s disease (AD), at the individual, family, community, and population level. The scope of this funding opportunity includes support for applications that propose the following: interventions to reduce caregiver burden and improve patient outcomes across various settings; population- and community-based research on the scope and impact of AD caregiving; improved characterization of informal and formal caregiving and the burden of caregiving across the full spectrum of the disease, including differences among socioeconomic, racial/ethnic and geographic sub-populations; and research addressing the unique challenges related to the provision of advanced AD care, including disparities in access to care. Grants are not limited but must reflect a budget; NIH expects to fund 12-16 awards up to a total of \$10 million. That would suggest an average grant of \$625,000. https://grants.nih.gov/grants/guide/pa-files/PAR-18-027.html</p>
<p>Alzheimer's Disease Supportive Services Program (ADSSP)</p>	<p>Creating and Sustaining Dementia-Capable Service Systems for People with Dementia and their Family Caregivers The objective of the Alzheimer’s Disease Supportive Services Program (ADSSP) is to expand the availability of dementia-capable support services for persons with Alzheimer’s Disease and Related Dementias (ADRD), their families and their caregivers. This goal will be achieved by: 1) enhancing the ability of state systems and programs to embed dementia-capability in their service networks; and 2) by delivering dementia-capable supportive services using evidence-based and/or evidence-informed interventions to support persons with dementia and their caregivers. The grantees receive targeted technical assistance provided by the National Alzheimer’s and Dementia Resource Center. Awards range from \$300,000 to \$650,000 https://www.acl.gov/grants/alzheimers-disease-supportive-services-program-adssp-creating-and-sustaining-dementia</p>

<p>American Occupational Therapy Foundation (AOTF)</p>	<p>Funding from AOTF would be requested to fund a pilot program or feasibility study. This most likely would be year two once the program is established, has been evaluated and is running with referral sources.</p> <p>Grants up to \$50,000 are available to help with research costs.</p> <p>http://www.aotf.org/aboutaotf/researchpriorities/familyandcaregiverneeds</p> <p>AOTF has identified Caregiver Burden as a priority area for funding research: Research Priority: Family and Caregiver Needs Addressing family and caregiver needs is a priority area across the lifespan, and in home and community settings. There is a great need for more effective interventions and improved outcomes for this population.</p> <p>It is estimated that over 18% of U.S. adults (over 43 million) have served as a caregiver for an adult or child with a disability or chronic health condition in the past year. Most care recipients are adults. 1 Caregivers address a variety of problems associated with physical conditions, memory impairments, emotional or behavioral problems, and intellectual/developmental / disabilities. 1 Caregivers report helping care recipients with activities of daily living (60%), instrumental activities of daily living (100%), and health care needs (>50%). 1 Over 40% of caregivers have a high level of caregiving burden based on their hours of care and almost 25% of caregivers report that this role has negatively affected their health. It is estimated that about 1/3 of caregivers provide 21 or more hours of care per week. 1 Approximately 8 out of 10 caregivers report they could use more information or help on special topics, including stress management, safety in the home, toileting, and handling problem behaviors. 1 Additional research on caregiving is needed to define its breadth and scope, estimate the economic impact, identify high risk factors, and develop effective interventions.</p>
<p>Tufts Health Plan Foundation</p>	<p>http://www.tuftshealthplanfoundation.org/index.php</p> <p>This foundation funds programs that foster healthy aging in New Hampshire, Massachusetts and Rhode Island. This grant would likely be sought to fund initiatives to expand the intervention at a community level in the future. They do not fund specific disease states however; they may fund programming that promotes people living at home longer. This type of grant may foster collaboration among agencies and</p>

	facilities to create a support network for caregiver of people with dementia. Average grant is \$100,000, applications must have a budget and be in line with the focus areas, one of which is caregiving.
Alzheimer's Association	Has a variety of research grants that fund research that leads to further understanding of the disease or improves the care of those living with Alzheimer's. Awards for studies and programs of this level would range from \$5000 to \$25000. (https://www.alz.org/research/alzheimers_grants/overview.asp) This would also be a year two grant to fund a research project.

Conclusion

Improving the Care Partner Experience: An Occupational Therapy Intervention for People with Dementia has a relatively modest start up. That is, year two costs will actually diminish from year one. As the intervention is reimbursable by Medicare and other commercial insurances, the program will eventually pay for itself and generate revenue for the facility, while meeting a critical need for clients with dementia and their care partners. Finally, as the program proves successful, there are grants and funds available to provide for the cost of a pilot program to demonstrate clinical efficacy and promote further adoption of this model for practice.

Chapter Six: Dissemination Plan

Improving the Care Partner Experience: An Occupational Therapy Intervention for People with Dementia is a program designed to educate and train a care partner in skills to promote functional engagement for their care recipient. The principles of the intervention were developed based on examining the problem and researching the current evidence for best practice guidelines. There is a low translation of the research evidence to clinical practice (Gitlin et al. 2015) thus a practice gap exists. This intervention outlines a clear and specific protocol based on self-efficacy theory, yet flexible to be client-centered and customized. Evidence indicates that increasing self-efficacy of the care partner will increase quality of life and reduce care partner burden. Therefore, this project establishes a clinic or telehealth-based treatment protocol that can increase occupational engagement of people with dementia through teaching their care partners skills that promote self-efficacy in caregiving. The goal of this project and development of this resource is to facilitate evidence translation to the clinic to reduce care partner burden and foster occupational engagement. A secondary goal will be to increase occupational therapy (OT) programs not only in my facility but in New Hampshire and Southern Maine.

Dissemination Goals

The long-term goal of this project is to establish a clinic or telehealth based treatment program for people with dementia and their care partners that is accessible, successful and cost effective. Currently there are limited outpatient OT programs designed to improve the care partner experience or increase occupational engagement for

the person with dementia.

Long term goals (1-3 years)

1. Clients with dementia and their care partners will have access to occupational therapy services that are client-centered, cost effective and accessible in the telehealth or clinic setting.
2. This program will demonstrate a significant positive change in outcome measures for quality of life, development of self-efficacy and reduction of burden for the care partner.
3. The program will be adopted in other area clinics as best practice and increase the availability of occupational therapy services for clients with dementia across the state.

Short Term goals (6 months to 1 year)

1. Two interested occupational therapists will be trained in providing the intervention and using the evaluation tools and clinic will have all necessary manuals and equipment.
2. Implementation of the program at the hospital the author works at with at least one referral per month over the first six months.
3. Program evaluation completed by reviewing feedback from clients, treating OTs, and client outcomes to revise the program and educational materials if needed.
4. Recommended changes to the program and manual implemented within one month of review for appropriateness and feasibility.
5. Educational opportunities for providers and the community promoting the

effectiveness of the intervention to increase referrals and increase adoption of this model in other OT clinics will occur within two months of initial program evaluation.

Target Audiences

There are two primary target audiences: 1) referring medical providers that would send their patients for this intervention and 2) community members that have a diagnosis of dementia and/or their care partners. They may in turn request referral to this intervention from the care provider. The secondary audience is occupational therapists interested in programs for people with dementia and care partners. With successful implementation, this program will serve as an example of a clinical translation of research in the area of dementia service delivery and as a model for that service. Occupational therapists are considered secondary as the client and the client's access to services is the primary goal of the intervention.

Key Messages

For providers:

1. Early recognition of dementia with early access to services can improve client and care partner quality of life, decrease burden and improve occupational engagement which will in turn reduce costs to the healthcare system.
2. Occupational engagement is progressively more difficult as dementia advances, yet not impossible. The goal of the program is that the care partner will learn techniques from an occupational therapist that will increase engagement and thereby decrease care partner burden in a cost effective manner that fosters self-

efficacy.

For clients and care partners:

1. Occupational engagement is important for health and well-being. Care partners will learn how to facilitate engagement, making caregiving less burden and more enjoyable.
2. Occupational therapists teach care partner skills to increase the participation of person with dementia in meaningful occupations. The plan of care is tailored to a client and care partner's specific needs, wants and desires. Effective occupational therapy is personal and pertinent to the individual situation.

For Occupational Therapists

1. The evidence supports interventions with care partners and people with dementia as effective when client-centered and fostering self-efficacy for desired caregiving tasks. By improving care partner self-efficacy, burden will decrease and quality of life (QoL) will increase.
2. Evidence of effective translation of research to practice is limited regarding OT intervention with people with dementia. OTs have an obligation to integrate evidence-based practice into clinic activities and increase services for clients with dementia and their care partners.

Messengers

Select key people are needed to assist in the dissemination of these messages: a physician champion, a care partner champion and an occupational therapist champion.

First, a geropsychiatrist working locally to speak to providers will provide important

guidance on diagnosing dementia in a timely fashion and emphasize the importance of early OT intervention. The geropsychiatrists at another local hospital have been working with OT's for over 20 years and are familiar with the services provided. Following successful completion of the program, a care partner will become another resource and key messenger. As a champion for the program, the care partner would speak at support groups for other care partners and marketing opportunities with providers. A peer who understands the caregiving experience will have the most credibility not only with other care partners but with referring providers. Finally, an occupational therapist that is experienced in delivering the intervention to speak to other occupational therapists and health professionals. Once established, ideally this program will be adopted in other facilities.

Dissemination Activities

Dissemination of the program would utilize several approaches: 1) developing written material, 2) speaking with provider groups, care partner and support groups and 3) developing posters and articles for occupational therapy professions. Written marketing materials, in the form of rack cards, that can easily be displayed and handed out will be produced. Success stories are a powerful tool that will be released via press release to local newspapers and subsequently shared to social media with the hospital's account. Advertising on social media and in online support groups will be another avenue to reach care partners. To address physicians, mailings can be done in addition to more effective face to face meetings. Documentation such as evaluations, plans of care and discharge summaries need to be clear, concise and show the appropriate progress as

they are sent to the referring provider. In this manner, if the physician refers a client and sees the documentation, he/she will be more likely to continue to refer future clients.

The physician champion will speak at a medical staff meeting or provide continuing education for providers (CME hours) as an opportunity to educate primary care providers on the signs of dementia and the effectiveness of timely referral to services such as occupational therapy. A physician speaking as an authority will increase the credibility of the message with other referring providers. Holding a CME forum on dementia and treatment will increase participation and the likelihood of primary care physicians hearing the message.

The occupational therapist, along with the care partner champion once identified, will provide community based lectures. These occur regularly at Wentworth-Douglass hospital and at a subsidiary, The Works Athletic Club. A community lecture will target current care partners that may have concerns and questions and are looking for solutions to the daily challenges. The community lecture would give general ideas but would direct the participants to request referral to an occupational therapist who is able to provide a client centered plan of care based on this protocol established in this project.

The care partner champion will speak informally with support groups and other care partner gatherings as appropriate, to spread the message of this program. Working with support groups, care managers and social workers, and local memory cafes to provide time on the agenda for the care partner to speak will be a best practice approach to ensure the appropriate timing. Hearing about the intervention from another care partner will facilitate credibility and buy-in on the part of other care partners. In addition,

care partner feedback for providers at meetings and quotes on marketing material will reinforce the impact of occupational therapy for clients.

With regards to dissemination of the program more globally to other OTs, a two-pronged approach will be utilized. Initially I will submit a proposal for a poster presentation at the 2019 New Hampshire Occupational Therapy Association (NHOTA) fall conference with another proposal for a poster presentation at the American Occupational Therapy Association (AOTA) annual conference in Boston in 2020. If accepted, these are excellent opportunities to explain the theoretical base and the evidence behind the intervention. Preliminary outcome data should be available at that time to share with other interested OTs. The second part of this approach would be writing an article with case studies for *OT Practice*. If these two activities generate enough interest, other educational opportunities would be pursued, such as providing a continuing education course teaching other therapists how to provide this intervention.

With regards to priorities, the written materials need to be designed and produced first, so that they are available at any lectures or talks given by any of the champions. The other activities do not need to happen in a specific order and will depend on facility, provider and champion schedules. A community lecture is likely to happen before health care provider education can be scheduled. Throughout this process, clear and timely documentation is always a priority. The presentations to AOTA and written articles will be subject to having data by the necessary deadlines, particularly for a poster presentation.

Budget

The first expense is the produced written materials. This cost is absorbed by the sponsoring hospital, Wentworth-Douglass Hospital. The primary expense related to the meetings and community lectures is therapist or physician time. In the funding plan, a total of \$780 dollars was related to paid time for marketing efforts. This equates to 14-20 hours of time. The facility also absorbs the cost of hosting the community lecture as a part of the hospital's mission is to provide the community with education.

Related to the poster presentation, travel and hotel expenses are expected to be paid by the therapist with personal funds. The primary therapist who would present will seek secondary funds to assist with travel, if available. These funds may come from educational institutions where she is adjunct faculty or her primary employers, the hospital. Otherwise they will be out of pocket. Time for writing an article for OT Practice will be done on the therapist's own time.

Table 6:1 Costs for Dissemination

Item	Cost Year One	Cost Year Two
Market Materials	Hospital marketing department to produce	same
Therapist time to market (14-20 hours)	\$780	\$460 (approximately 10 hours)
Facility costs (room, lights, snacks) for community lecture	Provided by hospital	same
Travel to Concord for NHOTA to present a poster 2018 (100 miles roundtrip)	\$55.00 mileage	\$55.00 if repeated
AOTA National Conference 2020 in Boston		\$1500 (hotel, conference fees, food, travel)
Total	\$835.00	\$510.00 without conference fees (2015.00 if facility supports OT conference attendance)

Evaluation

An increase number of referrals to the occupational therapy department for this intervention will be the primary benchmark of success of the dissemination plan. The author of this project will be able to track the number of referrals with a diagnosis of dementia and the number of times this intervention is utilized by the trained OT's. If that number increases by 10% over six months, the dissemination efforts will be considered successful. The author will also track requests for information by phone, email and online. An increase in requests for information will also signal that that dissemination efforts are successful.

With regards to dissemination efforts to other OT's who work at other facilities, this will also be tracked by requests for more information. An email contact will be used in educational material both at the poster presentation and in the article. If requests grow, further success will be demonstrated by the development and success of a continuing education program.

Conclusion

As identified in my original problem, access to early diagnosis of dementia and timely services is limited in rural areas. With appropriate dissemination activities, this program can facilitate easier, more timely access to occupational therapy for people with dementia and their care partners. As the success of the program grows locally, further dissemination goals can spread the program into more clinics with an expanded base of providers. Monitoring referrals and requests for information will evaluate the success of

dissemination efforts and provide feedback regarding the need to change those efforts.

Finally, the budget for dissemination is reasonable and supports a successful effort.

Chapter Seven: Conclusion

Improving the Care Partner Experience is a project based on the identification of a problem, examination of current practice and theory, and development of a protocol to provide an occupational therapy service that is client centered and effective. The goal of the intervention is to foster occupational engagement for people with a diagnosis of dementia, supporting them to function at their highest ability while concurrently building a sense of self-efficacy for the care partners, decreasing burden and improving quality of life. Occupational therapy is uniquely suited to address the performance decline and subsequent risk of institutionalization that occurs in the progression of dementia. The program described in this doctoral project fits with the American Occupational Therapy Association (AOTA) Vision 2025: “Occupational therapy maximizes health, well-being, and quality of life for all people, populations, and communities through effective solutions that facilitate participation in everyday living.” (AOTA, 2017, p1).

The elements contributing to the problem are outlined in the first chapter. In New Hampshire, access to quality services can be limited by the rural nature of the state. People may have to travel up to two hours by car to see a geropsychologist located in the southern half of the state. Further complicating access are the limited programs that are available for people with dementia and their care partners. Gitlin, Marx, Stanley, and Hodgson (2015) provide data outlining a lack of programming, with only one percent of the research on dementia being used in clinical practice. Current treatment programs exist, but take place through homecare, which requires being homebound, or unable to leave the home easily. Many older people with dementia do not meet that criteria. This

creates a practice gap that needs to be filled, as the number of people diagnosed with Alzheimer's and related dementias continues to climb yearly (Alzheimer's Association, 2017).

In the second chapter, the problem is further defined and supported by evidence. New Hampshire is a rural state with limited programs. The number of people living with dementia and the informal care partners that support them at home is growing significantly. Those care partners are often not equipped to provide care and are subject to increased levels of burden and illness, both physical and psychological. Programs designed to increase self-efficacy have more significant positive results in decreasing burden than educational programs (Crellin, Orrell, McDermott, & Charlesworth, 2014; Semiatin & O'Conner, 2012). These programs include telehealth programs, as long as they have a personal component, such as a live coach, and not solely email (Jackson, Roberts, Wu, Ford, and Doyle, 2016). Occupational therapy is uniquely suited to foster self-efficacy for caregiving. Yet, surveys of OT practitioners suggest that treatment for dementia can be limited by therapist comfort level and setting (Bennett, Shand, & Liddle, 2011; Gately & Trudeau, 2017; McGrath & O'Callaghan, 2013; Swinson, Wenborn, Hynes, Orrell, Stansfeld, Rooks, & Ledgerd, 2016).

The state of current evidence was then explored, identifying two OT programs in particular that have significant evidence of improving occupational engagement, increasing care partner self-efficacy and increasing quality of life for both members of the care dyad. Other programs were examined but most lacked a client-centered component that focused on specific tasks and environments. The most effective

programs incorporated education and practice on task and environment modification with improving communication skills. Other programs that only focused on one aspect or did not apply the information in a personal manner did not have significant results. Those programs that had the best results occurred in the home setting, one in the Netherlands and one program in the United States. Clinic based settings did not demonstrate significant positive results. Most of the clinic-based programs were educational in nature, provided in group settings and not personalized to the client.

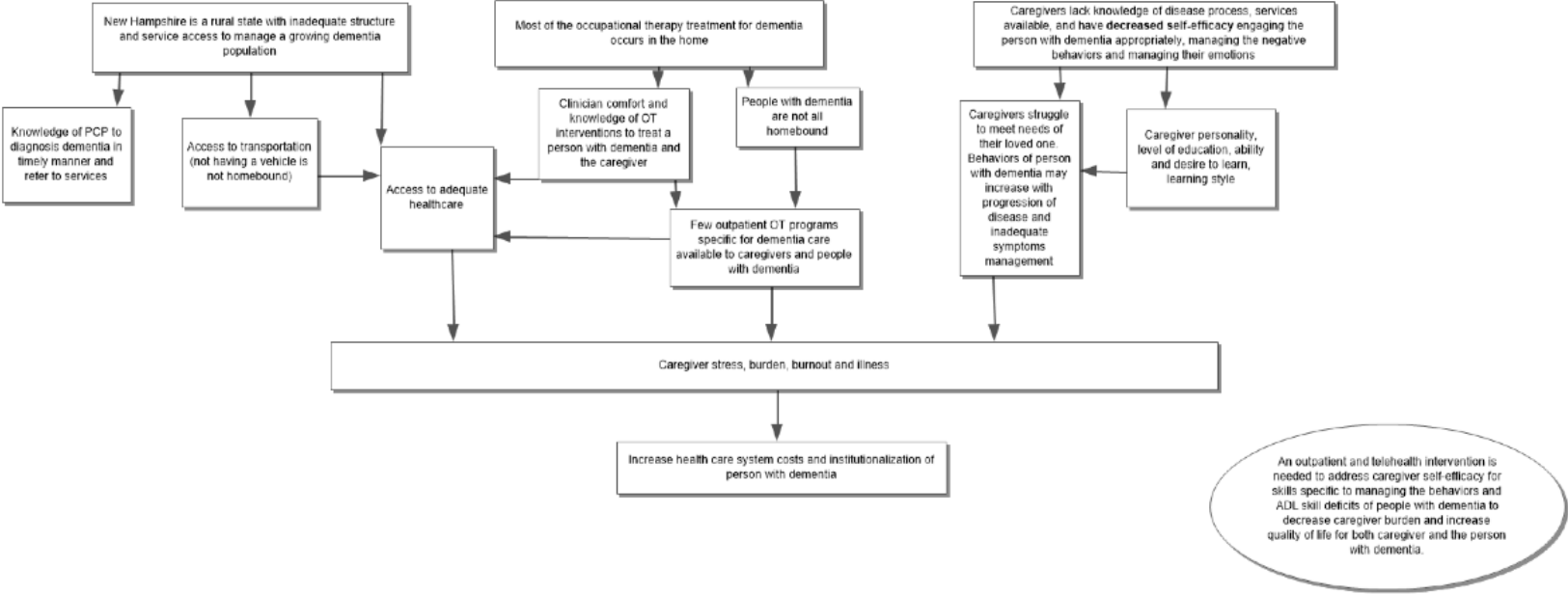
Using the elements that research indicated contributed the most to a successful intervention, *Improving the Care Partner Experience* was designed to be client-centered and focus on the occupations that mattered most to the care dyad. A combination of evaluation, education and practicing skills was utilized in a clinic setting. The intervention itself is fully outlined in chapter three and the template for education is available in Appendix B with a full case study in Appendix C. In this manner, *Improving the Care Partner Experience* can be easily integrated in a standardized, reproducible manner that retains its personal client-centered focus. Further, the program lends itself to telehealth, particularly video-based interaction, to reach the rural areas of NH, eliminating access barriers.

By virtue of being reproducible and standardized in content delivery, *Improving the Care Partner Experience* lends itself to research and contributing to the OT evidence base. Chapter Four is a program evaluation plan, that additionally could be used as the basis for single subject design or larger research. Demonstrating efficacy and effective interventions, especially for clients with dementia, creates value for the profession of

occupational therapy in an ever-changing health care climate. Competition for reimbursement and health care dollars is growing. Increasing our evidence base and creating best practice protocols will contribute to the profession's viability in the future.

Therefore, this doctoral project contributes to the field of occupational therapy by translating the research into a clinic or telehealth-based protocol that is driven by evidence. The flexibility of the program is innovative yet in line with the vision of AOTA by maximizing the occupational engagement of an at-risk population that is currently underserved with effective tools creating positive solutions. As a client-centered, occupation-based protocol, *Improving the Care Partner Experience* can be widely implemented filling a current practice gap and contributing to the quality of life of occupational therapy consumers.

Appendix A: Explanation of the Problem



Appendix B: Template of Client/Care partner education

Helping a person with dementia can be frustrating. Below are strategies that can help ease frustration and make caregiving less stressful. Not every strategy is right for every person. You will be working with the occupational therapist to learn which strategies are best suited for your situation and practice using them with guidance until you feel comfortable.

Remember: no one is perfect and using new methods takes time. Your loved one is not being deliberately stubborn and truly does have difficulty with everyday activities. They still want to perform their daily activities and be independent. Sometimes new routines can be developed, sometimes they cannot. Your occupational therapist will help set realistic expectations and maximize performance.

The goal of occupational therapy is to help both you and your loved one continue to do the things that are important to both of you.

The types of problems encountered at home might include:

- Distractibility and poor attention to detail
- Inability to problem solve a novel task or when a familiar task does not go as expected
- Inability to complete tasks once started or not knowing something is done
- Difficulty initiating activities despite the intent to do something
- Poor visual perceptual skills--can make doing puzzles hard, or finding objects in a drawer with other things present difficult
- Resistive behavior--not wanting to bathe or dress, resisting leaving the house
- Wandering--even if not trying to leave, pacing in the house
- Fatigue
- Poor memory-not remembering conversations or locations of objects
- Persistent behavior--asking the same question over and over like the date or when a meal is or what the schedule for the day is
- Impaired safety concerns - using tools inappropriately
- Difficulty following directions, especially verbal
- Withdrawal from social activities - not wanting to see friends or difficulty with conversation

Environment—what is happening around you can either help or hurt your ability to do any given task. Noise and visual inputs can cause distraction. On the other hand, using soft music or visual contrast can help attention. The environment can be used to cue someone what to do next or confuse them with too many choices. Here are tips for changing the environment to support performance:

- Turn off TV, radio, other sources of noise during tasks, especially if sound has talking or lyrics
- Consider quiet music without words in the background
- Reduce visual clutter--limit extra items on counter or tables and other work surfaces to only needed items
- Make sure the needed objects are obvious, when leaving out an activity
- Use a contrasting background when appropriate for the activity (use a large solid placemat)
- Remove scatter rugs which can cause tripping and may cause visual confusion
- Label drawers with simple labels: “pants”, “silverware”, “bowls”. Avoid extra words or language on labels
- Make labels large enough to see and a color that stands out (not a light color on a white cabinet)
- Keep sharp or dangerous objects put away or even in locked drawer
- Create a visual border for the work area--colored tape, a ruler, a placemat
- Use timers and alarms to increase independence with identifying rest breaks or times to move to next activity.
- Use a large calendar for orientation
- Create a list of day’s activities and appointments for person with dementia to refer to throughout the day

Specific recommendations for you and your loved one:

- _____
- _____
- _____
- _____

Communication—the way a task or activity is presented can change how someone responds or participates. When there is a memory issue, it can be hard to communicate the same way. Too much or too little information can make a difference. It is easy to get frustrated or to do it yourself instead of having your loved one perform the activity. Here are some ways that could make giving direction easier:

- Use simple direct cues, be directive
- Provide visual demonstration with limited verbal instruction during the demonstration
- Use tactile cues gently
- Cue step by step if needed. Give only one step at a time to avoid giving confusing directions or too much information

- Wait until one step is complete to cue the next step.
- Use a calm tone of voice; count to 10 before responding if not feeling calm
- Provide a choice of 2 acceptable options (Do you want to put the red shirt or blue shirt on? Not “do you want to get dressed”)
- Wait at least 10 seconds for processing before repeating cues
- Don’t elaborate on instruction or explain
- Try not to argue; redirect towards the task or answer the question simply
- Determine and provide level of supervision needed
- Allow extra time for processing of information and task performance
- Be accepting if task not completed “perfectly” when safety is not an issue
- Use positive feedback for successful engagement or completion

Specific recommendations for you and your loved one:

- _____
- _____
- _____
- _____

Activities—activities that used to be easy or second nature may be more difficult now. A person with dementia may have trouble getting started and then be fine, or they may have difficulty sequencing each step and need assistance throughout the task. “Keeping busy” is important to help your loved one feel purposeful and capable despite their challenges and therefore, engaging in the activity is much more than just keeping busy.

- Identify the steps of the activity
- Provide tasks that are meaningful--either self-care or something of interest to the person with dementia.
- Assist with the sequencing of the task
 - Set out the needed items in the appropriate order
- Use a list with steps of task if appropriate
- If the entire task is too much, decide which steps are appropriate
 - For example, completing an entire recipe may be too much, but performing 3 of 5 steps may be appropriate with help using the stove at the beginning and end
- Respect fatigue: make sure that rest breaks are built in or that the task can be stopped if fatigue interferes with performance
- Set out clothing in the appropriate order for dressing tasks
- Make sure items are clearly labeled

- Label the shampoo, conditioner and body soap with large writing. Can use a sharpie
- Assure that the toothpaste is visible and clearly labeled and correct toothbrush obvious
- Label tools with reminders for function when practical--gardening, craft, cooking

Specific recommendations for you and your loved one:

- _____
- _____
- _____
- _____

Managing behaviors—sometimes a person with dementia starts behaving in ways that are surprising and difficult to manage both dealing with the behavior in the moment and feeling emotional over the changes you are seeing. Many of the common behaviors can be managed or redirected with these tips:

- Repeated questioning
 - Answer simply and calmly
 - Redirect-
 - If question is about the date or appointments, direct them to the calendar
 - If the question is related to daily schedule—“did we have lunch?” use a schedule and redirect to the time and schedule
 - If it is not possible to redirect to the answer, try engaging in an occupation that is enjoyable.
- Resistive to care
 - Offer 2 acceptable choices
 - “Do you want to wear this shirt or that shirt?”
 - Do you want to take the shower now or after breakfast?
 - Do you want to help me cook lunch or do a puzzle?
- Do not request compliance, be slightly directive (but respectful)
 - Let’s get dressed vs. Do you want to get dressed?
 - It’s time to do (activity or meal)
- Difficulty with transitions
 - Give time for processing--if leaving the house, give warning ahead and then remind frequently with a timer or direction toward clock if needed.
 - Plan the day accordingly--don’t rush bathing and dressing to get out the door

- Allow more time to complete tasks including meals
- Paranoid or angry behavior
 - Try not to take it personally, as the person with dementia believes the misdirected thought
 - Try to respond pleasantly but not belittling
 - Be firm but slightly directive
 - Do not attempt to reason or argue--rational arguments are not possible when the person is in this state
 - Redirect to a desired and enjoyable activity
 - Use stress management techniques to stay calm
 -

Specific recommendations for you and your loved one:

- _____
- _____
- _____
- _____

Stress Management—it is really important that as a care partner, you take time for your needs. It is often an overwhelming job but can be very satisfying. Always take some time for the following:

- Take deep breaths and count to 10 when having difficulty containing emotion
- Take breaks whenever possible
- Get important things done while loved one is engaged in an activity
- Try to get sleep, eat healthy and exercise
- Ask for help
- Use respite services
- Listen to relaxing music
- Take time for relaxing hobbies
- Don't worry about a perfect house and perfect meals
- Try a meditation app or program

Specific recommendations for you and your loved one:

- _____
- _____
- _____
- _____

Appendix C: Case Scenario

Mary is a 75-year-old woman who moved to New Hampshire from the mid-west with her husband six months ago to be closer to their daughter. Their daughter is present at the evaluation and goes to visit her parents regularly through the week to assist them. Mary and her husband live in an elderly apartment complex that does not have services for individual residents or community meals but does have organized activities available, such as exercise class. Her daughter states that Mary was having some issues with memory before moving but those issues seem significantly worse now. Prior to moving, Mary was very active and had many friends. She participated in exercise classes and would go to lunch and shopping with friends regularly. On the other hand, her husband is shy and not interested in social activities. She reports her mother is experiencing a more than six-month history of deterioration of gait and memory. Now with a shuffling gait, balance issues and needing a walker, Mary has been evaluated by several physicians including her primary care physician and two neurologists. They have ruled out Parkinson's and peripheral neuropathy. The MRI showed vascular changes and the neurologist diagnosed Mary with vascular dementia. No follow up with neurology is scheduled.

Mary's daughter goes into the home several times a week to help Mary and talks with her daily on the phone. Mary's husband does all the cooking but does not help Mary with personal care. At this point, Mary is able to dress herself daily without assistance. Through interview, her daughter identifies some challenging areas: 1) Mary calls her daughter multiple times a day, every day. Mary will argue with her daughter about when

she called last and does not remember what they agreed on within the conversation—her daughter will give her a day and time for a visit and Mary will need the information repeated until her daughter refuses to say it again. Mary will perseverate on the calendar at home and ask what time appointments are occurring repeatedly. Her daughter feels there is an anxiety component involved in Mary's behavior 2) Mary does not get to participate in any social activities. Her husband brought her to an exercise group one time but has not returned. He does not enjoy going out so he does not take Mary out. 3) Mary can't shower by herself. Her daughter tries to assist but Mary takes up to an hour to complete a shower, often staring off into space and not sequencing the activity well 4) Mary doesn't do crosswords like she used to and no one has brought her puzzle books since she moved to NH for her to try. She really enjoyed working on these puzzles in the past.

Mary has strengths: she can read and follow a calendar, she enjoys being social and has made acquaintances at her new apartment complex, she is independent in dressing. She remembers the past and her new friends and does well having conversations. On the other hand, Mary also has challenges. Her memory could be impacted by attention, concentration and anxiety. She has just experienced a significant change in her environment and routines. Her mobility issues are impacting her ability to get around safely and be as active as she once was.

Evaluation Findings

An assessment of Mary's skills was performed with the following measures: COPM, Montreal Cognitive Assessment (MoCA), Executive Function Performance Test

(EFPT) and the Allen Cognitive Level Screen (ACLS). Mary's daughter completed the CarerQoL, Short Form Zarit Burden Interview and Revised Scale for Caregiver Self Efficacy. Mary had the following scores:

MoCA: The MoCA score ranges from 0 to 30, with 30 being a perfect performance. A score under 26 is considered mild cognitive impairment or dementia. Mary scored 15/30 with a clock and cube that show visual perceptual deficits with poor spacing. No long term recall and difficulty with serial 7s. Generally limited executive function, visuospatial and delayed recall skills.

ACLS: The ACLS scores range from 0-6 with 6 being totally independent. Each level is defined by the performance on the task, which is administered by a protocol in the manual for the test, and has a functional description for the level of cognition. Mary scored a 4.2 on the leather lacing which is consistent with: Close supervision to remove dangerous objects outside of the visual field and to solve any problems arising from minor changes in the environment. Person may spend a daily allowance, walk to familiar locations in the neighborhood, or follow a simple, familiar bus route.

EFPT: Possible scores on tasks range from 0-25, on skill components from 0-20 and total score 0-100. 0 is completely independent for all categories. Task scores as follows: 1) Simple Cooking: 9 2) Using the telephone: 8, 3) Taking Medication: 9, 4) Paying Bills: 9. Component scores are: 1) Initiation: 6, 2) Organization: 4, 3) Sequencing: 13, 4) Judgement & Safety: 10, 5) Completion: 3. Total score is 36. Results indicate Mary has difficulty with sequencing, making judgements and performing tasks safely. She needed verbal support and direction throughout the evaluation.

COPM: a list of 5 occupational performance problems was developed based off a comprehensive interview with Mary and her daughter. Scores are the daughter's rating of Mary's performance and the daughter's satisfaction on a scale of 1-10 with 0 equal to poor performance/not satisfied and 10 equal to independent/fully satisfied. Mary was included in the discussion and agreed with her daughter's ratings. They are:

Occupational Performance Problem	Performance Score (out of 10)	Satisfaction Score (out of 10)
1. Completing a shower	3	3
2. Participating in exercise class held in apartment complex	5	5
3. Keeping track of the date and times of appointments, feeling like she knows her schedule	3	4
4. Participating in light meal prep	3	7
5. Doing word puzzles	4	2
Scores (total/number of problems)	18/5= 3.6	21/5= 4.2

Mary's daughter completed care partner assessments and her results are as follows:

The Revised Scale of Caregiver Self-Efficacy: Scores are on a Likert scale of 0-100 where 0 is unable to manage the task and 100 is fully able to manage the task. Therefore, a higher number is related to higher self-efficacy. Mary's daughter felt able to obtain help but had more difficulty with responding to behavior and controlling her own upsetting thoughts when considering caring for Mary.

For Obtaining Respite: 450/500

For Responding to Disruptive Behaviors: 250/500

For Controlling Upsetting Thoughts: 270/500

Carer QoL: Mary's daughters' answers indicated some support and some stress with caregiving tasks but did not indicate any problems with mental health items. Her score

for current happiness/satisfaction on a 1-10 Likert scale where 1 is completely unhappy and 10 is completely happy was 5.5

Short Form Zarit Burden Interview: Mary's daughter scored a 17, indicating mild to moderate burden. A score between 10 and 20 indicates mild to moderate burden. Over 20 is significant burden.

After reviewing the evaluation results, the following written plan was given to Mary, her daughter and her husband:

Proposed Treatment Plan

Occupational Therapy 1x/week or every other week with 5 visits after the first visit for evaluation over the course of 10 weeks with Mary and her daughter and her husband if possible for therapeutic activity, self-care/home management training, and patient and family education. The following goals are established:

1. Mary will orient herself to the date, appointments and when she is able to call her daughter, using a calendar or planner, with cues directing her to the calendar as needed.
2. Mary will complete a shower in less than 30 minutes with environmental supports, appropriate verbal and tactile cueing and minimal physical assist.
3. Mary will participate in leisure activities (e.g. word puzzles and exercise classes) with appropriate environmental supports and minimal assistance from her care partner as needed.

4. Mary will demonstrate increased engagement in activities, as measured by an increase of ≥ 2 points on the COPM performance and satisfaction scores, demonstrating a clinically significant change.

Each visit after the evaluation follows a format designed to increase the care partner's ability to implement the strategies outlined in the written plan given to the care partner.

In Mary's case, treatment will focus on using the strategies to increase her ability to use a visual schedule, perform ADL tasks and participate in social/leisure activities. Each visit follows a format: 1) Review the strategies and tasks used in the time period from the previous visit to problem solve or reinforce performance 2) Introduce the strategies and task to work on this week; therapist will model how to engage Mary in the task using the strategies if needed 3) Have the care partner engage Mary in the task 4) Feedback and problem solving with the OT to refine the task. The OT must give positive and encouraging feedback throughout the course of treatment along with constructive feedback, as part of the development of self-efficacy. Each visit time is spent on verbally planning how to translate the clinic task to the home. A general outline of visits for Mary would be as follows:

Visit 1: Evaluation

Visit 2: Review written suggestions with Mary's daughter and Mary (see plan at end).

First task: using a daily schedule or calendar. Using a sample daily calendar, fill in several appointments and scheduled phone calls. Demonstrate introducing the schedule to Mary and have her daughter practice using planner with Mary. The daughter would work with Mary to check the planner, check the time and understand the task. Refine

strategies and modify the activity based on Mary's performance until she is successful.

Honor Mary's preferences in setting up the schedule. Discuss with Mary and her family and problem solve any barriers to implementation at home. Develop a plan for attending exercise class and make sure it is on her schedule. Mary is unable to navigate to and from the class but can attend without her family present. Ask Mary's daughter to bring in video of the bathroom set up next week to start working on showering task.

Visit 3: Review how using a planner is working with Mary and her family, revise suggestions as needed to address any issues with implementation. Discuss any barriers or facilitators to attending exercise class—ask Mary how she enjoyed going. Review video of bathroom and environment and make suggestions on adapting the bathroom environment. Perform a simulated task that requires Mary to cognitively attend and participate like the shower (without the shower), having her daughter facilitate the task after demonstration. The focus of the session should be using the written strategies to facilitate performance, especially focusing on how to give cues—slowly, directly, with minimal language. Discuss ways to modify the task and environment not only for the daughter but for a potential future paid care partner. Make sure the environment is not visually cluttered. Practice a tub transfer in the clinic using the tub bench to practice the skills with her family and Mary. Give the daughter resources for obtaining help at home, including the name and contact information for the hospital social worker.

Visit 4: Review showering and practice any skills discussed in previous visits that are unclear or did not work. Review using the calendar/schedule and ask if Mary is attending exercise class. Reinforce the strategies that did work. Work on word puzzles during this

session. Have Mary perform puzzles of varying level of difficulty and determine the most difficult level that she can be successful with, both by herself and with support. Demonstrate environmental modifications that would help Mary's success, including limiting distractions, creating a visual focus with colored placemats and making sure she has appropriate puzzles laid out. Discuss with her family how to perform higher level puzzles with verbal and tactile cues, creating an activity they could do together. Explore with family how they could do this without stress and find enjoyment participating socially with Mary. Include reinforcing stress management techniques.

Visit 5: Review previous visits and problem solve challenges, celebrate successes. The last two visits are flexible to revisit any of the previous tasks to facilitate care partner confidence using the written strategies in daily life. Ideally, introduce a novel task such as preparing a light snack using the toaster and have the care partner facilitate Mary's performance without demonstration from the OT. Give feedback and problem solve any challenges. This allows for generalization of skills on the part of the care partner and will facilitate self-efficacy in using the written strategies.

Visit 6: Review the course of treatment. Spend session on any questions or practicing any skills not mastered. Re-evaluate with outcome measures.

Example Written Plan

Helping a person with dementia can be frustrating. Below are strategies that can help ease frustration and make caregiving less stressful. Not every strategy is right for every person. You will be working with the occupational therapist to learn which strategies are best suited for your situation and practice using them with guidance until you feel comfortable.

Remember: no one is perfect and using new methods takes time. Your loved one is not being deliberately stubborn and truly does have difficulty with everyday activities. They still want to perform their daily activities and be independent. Sometimes new routines can be developed, sometimes they cannot. Your occupational therapist will help set realistic expectations and maximize performance.

The goal of occupational therapy is to help both you and your loved one continue to do the things that are important to both of you.

The types of problems encountered at home might include:

- Distractibility and poor attention to detail
- Inability to problem solve a novel task or when a familiar task does not go as expected
- Inability to complete tasks once started or not knowing something is done
- Difficulty initiating activities despite the intent to do something
- Poor visual perceptual skills--can make doing puzzles hard, or finding objects in a drawer with other things present difficult
- Resistive behavior--not wanting to bathe or dress, resisting leaving the house
- Wandering--even if not trying to leave, pacing in the house
- Fatigue
- Poor memory--not remembering conversations or locations of objects
- Persistent behavior--asking the same question over and over like the date or when a meal is or what the schedule for the day is
- Impaired safety concerns - using tools inappropriately
- Difficulty following directions, especially verbal
- Withdrawal from social activities - not wanting to see friends or difficulty with conversation

Not all these suggestions may apply to your situation. Your therapist has highlighted those that are felt to be important for you and has added in specific suggestions.

Environment—what is happening around you can either help or hurt your ability to do any given task. Noise and visual inputs can cause distraction. On the other hand, using soft music or visual contrast can help attention. The environment can be used to cue

someone what to do next or confuse them with too many choices. Here are tips for changing the environment to support performance:

- Turn off TV, radio, other sources of noise during tasks, especially if sound has talking or lyrics
- Consider quiet music without words in the background
- Reduce visual clutter--limit extra items on counter or tables and other work surfaces to only needed items
- Make sure the needed objects are obvious, when leaving out an activity
- Use a contrasting background when appropriate for the activity (use a large solid placemat)
- Remove scatter rugs which can cause tripping and may cause visual confusion
- Label drawers with simple labels: “pants”, “silverware”, “bowls”. Avoid extra words or language on labels
- Make labels large enough to see and a color that stands out (not a light color on a white cabinet)
- Keep sharp or dangerous objects put away or even in locked drawer
- Create a visual border for the work area--colored tape, a ruler, a placemat
- Use timers and alarms to increase independence with identifying rest breaks or times to move to next activity.
- Use a large calendar for orientation
- Create a list of day’s activities and appointments for person with dementia to refer to throughout the day

Specific recommendations for you and your loved one:

- **Use a day planner with a single day available to look at, to limit focus on future dates and appointments. Be specific with times for events for the day with a cue to look at the clock.**
- **Schedule times in the planner for phone calls. Make sure you are available at those times but limit the unscheduled phone chats (when you answer, remind her of the time she is to call and tell her you are unable to talk. Don’t ignore the call, she may just keep calling if her anxiety increases).**
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Communication—the way a task or activity is presented can change how someone responds or participates. When there is a memory issue, it can be hard to communicate the same way. Too much or too little information can make a difference. It is easy to get frustrated or to do it yourself instead of having your loved one perform the activity. Here are some ways that could make giving direction easier:

- Use simple direct cues, be directive
 - Provide visual demonstration with limited verbal instruction during the demonstration
- Use tactile cues gently
- Cue step by step if needed. Give only one step at a time to avoid giving confusing directions or too much information
- Wait until one step is complete to cue the next step.
- Use a calm tone of voice; count to 10 before responding if not feeling calm
- Provide a choice of 2 acceptable options (Do you want to put the red shirt or blue shirt on? Not “do you want to get dressed”)
- Wait at least 10 seconds for processing before repeating cues
- Don’t elaborate on instruction or explain
- Try not to argue; redirect towards the task or answer the question simply
- Determine and provide level of supervision needed
- Allow extra time for processing of information and task performance
- Be accepting if task not completed “perfectly” when safety is not an issue
- Use positive feedback for successful engagement or completion

Specific recommendations for you and your loved one:

- **In the shower, limit any visual distractions. Use simple verbal or tactile cues to keep Mary engaged when she stares into space or doesn’t initiate the next step.**
- **Redirect to her calendar or day planner when she is asking repeated questions about dates and times. Don’t argue and keep repeating the information.**
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Activities—activities that used to be easy or second nature may be more difficult now. A person with dementia may have trouble getting started and then be fine, or they may have difficulty sequencing each step and need assistance throughout the task. “Keeping busy” is important to help your loved one feel purposeful and capable despite their challenges and therefore, engaging in an activity is much more than just keeping busy.

- Identify the steps of the activity
- Provide tasks that are meaningful--either self-care or something of interest to the person with dementia.
- Assist with the sequencing of the task
 - Set out the needed items in the appropriate order
- Use a list with steps of task if appropriate—could laminate a sheet of instructions in shower
- If the entire task is too much, decide which steps are appropriate
 - For example, completing an entire recipe may be too much, but performing 3 of 5 steps may be appropriate with help using the stove at the beginning and end
- Respect fatigue: make sure that rest breaks are built in or that the task can be stopped if fatigue interferes with performance
- Set out clothing in the appropriate order for dressing tasks
- Make sure items are clearly labeled
 - Label the shampoo, conditioner and body soap with large writing. Can use a sharpie
 - Assure that the toothpaste is visible and clearly labeled and correct toothbrush obvious
 - Label tools with reminders for function when practical--gardening, craft, cooking

Specific recommendations for you and your loved one:

- **Mary is not anxious attending organized activities without her family. Her husband could drop her off at exercise class and pick her up after. Class should be marked clearly on day planner. He does need to be timely to avoid triggering anxiety.**
- **Mary is making new friends. Since her husband does not enjoy going out, encouraging her friends to include her in social activities may be helpful.**
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Managing behaviors—sometimes a person with dementia starts behaving in ways that are surprising and difficult to manage both dealing with the behavior in the moment and feeling emotional over the changes you are seeing. Many of the common behaviors can be managed or redirected with these tips:

- Repeated questioning
 - Answer simply and calmly
 - Redirect-
 - If question is about the date or appointments, direct them to the calendar
 - If the question is related to daily schedule—“did we have lunch?” use a schedule and redirect to the time and schedule
 - If it is not possible to redirect to the answer, try engaging in an occupation that is enjoyable.
- Resistive to care
 - Offer 2 acceptable choices
 - “Do you want to wear this shirt or that shirt?”
 - Do you want to take the shower now or after breakfast?
 - Do you want to help me cook lunch or do a puzzle?
- Do not request compliance, be slightly directive (but respectful)
 - Let’s get dressed vs. Do you want to get dressed?
 - It’s time to do (activity or meal)
- Difficulty with transitions
 - Give time for processing--if leaving the house, give warning ahead and then remind frequently with a timer or direction toward clock if needed.
 - Plan the day accordingly--don’t rush bathing and dressing to get out the door
 - Allow more time to complete tasks including meals
- Paranoid or angry behavior
 - Try not to take it personally, as the person with dementia believes the misdirected thought
 - Try to respond pleasantly but not belittling
 - Be firm but slightly directive
 - Do not attempt to reason or argue--rational arguments are not possible when the person is in this state
 - Redirect to a desired and enjoyable activity
 - Use stress management techniques to stay calm
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Specific recommendations for you and your loved one:

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Stress Management—it is really important that as a care partner, you take time for your needs. It is often an overwhelming job that can be very satisfying. Always take some time for the following:

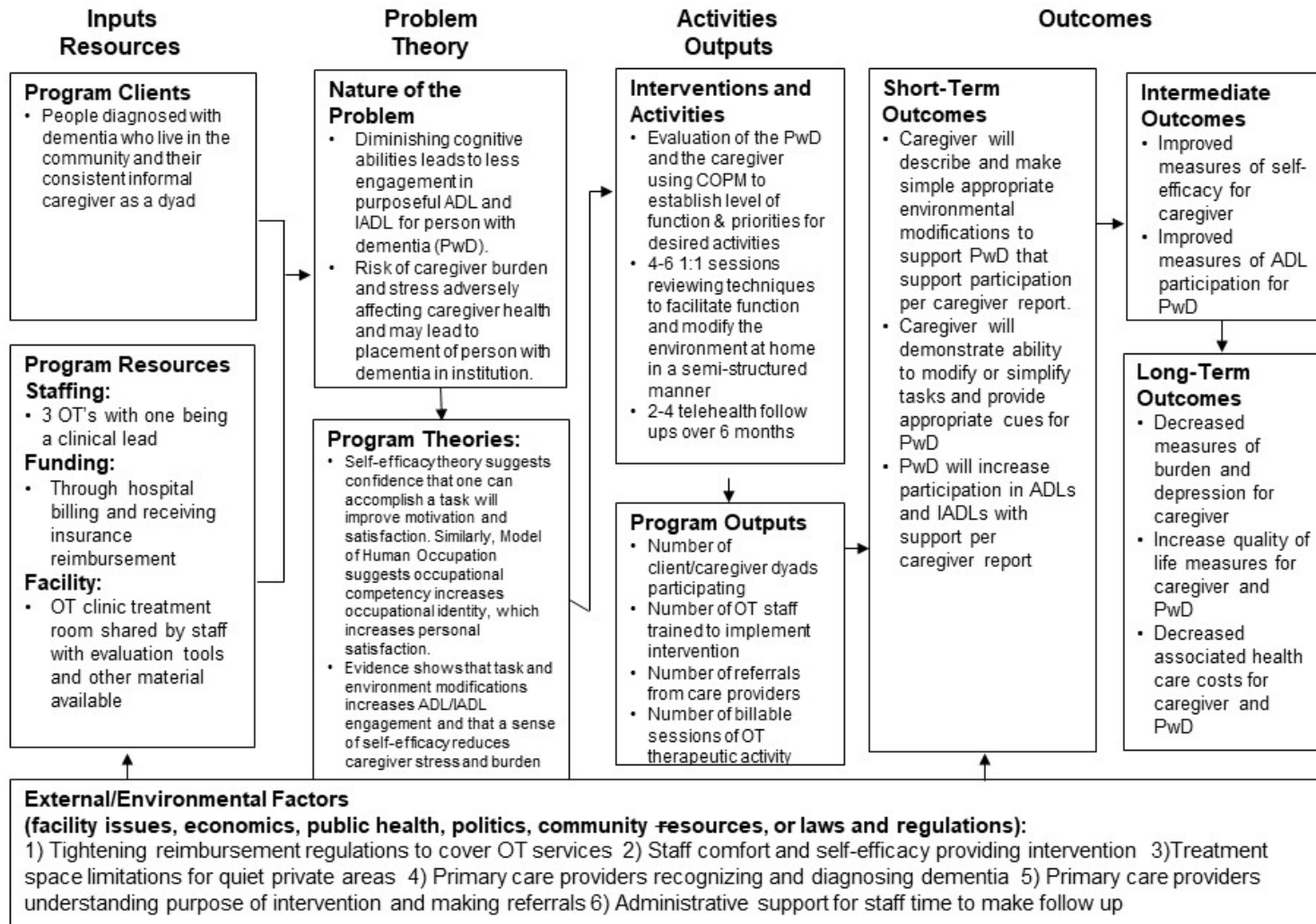
- Take deep breaths and count to 10 when having difficulty containing emotion
- Take breaks whenever possible
- Get important things done while loved one is engaged in an activity
- Try to get sleep, eat healthy and exercise
- Ask for help
- Use respite services
- Listen to relaxing music
- Take time for relaxing hobbies
- Don't worry about a perfect house and perfect meals
- Try a meditation app or program

Specific recommendations for you and your loved one:

- **Getting a paid companion to spend time with Mary and take her places is an excellent idea—OT can provide the name and number of the hospital social worker to pursue.**
- **Find time to spend socially with your mom/spouse and not just in the care partner role of providing assistance with daily activities. Do puzzles together, go out for coffee, play games. During the course of OT, we will explore which puzzles and games are the most suited to Mary's skills to promote enjoyment and fun.**
- **Take Mary to exercise class and pick her up without staying. Use the time to get things done or to relax and do something you enjoy.**

Appendix D: Logic Model for Program Evaluation

Dementia Caregiver Intervention



Appendix E: Executive Summary for *Improving the Care Partner Experience: An Occupational Therapy Intervention for People with Dementia*

Introduction

Fifteen million Americans are informal care partners for five million people currently diagnosed with Alzheimer's Disease (Alzheimer's Association, 2017). These care partners are at risk for illness related to stress and burden, while the care recipient is at risk for nursing home placement. People diagnosed with Alzheimer's Disease experience a variety of symptoms and behaviors. These include: challenges in problem solving everyday tasks, completing familiar activities (even those as basic as bathing), and withdrawal from social activities. In turn, the individuals reduce their occupational, or activity, engagement (Alzheimer's Association, 2017). Care partners often struggle to support people with dementia, perceiving their behaviors as stubborn and uncooperative (Alzheimer's Association, 2017; Cepoiu-Martin, Tam-Tham, Patten, Maxwell and Hogan, 2016). According to the Alzheimer's Association (2017), the cost of care partner illness and stress is \$10.9 million. The leading causes of nursing home placement are the inability to perform activities of daily living, such as bathing, dressing, and grooming independently, and behaviors such as resistance to care and wandering (Buhr, Kutchibhatla, & Clipp, 2006). Aging in place is more cost effective than nursing home placement (Marek, Stetzer, Adams, Popejoy and Rantz, 2012), therefore efforts to reduce care partner burden and promote aging in place are critical.

In New Hampshire, the rural nature of the state and the limited availability of occupational therapy (OT) programs for people with dementia reduces access to services

that may influence caregiver burden. Limited public transportation and the need to travel long distances to facilities creates barriers for service recipients. Clients that could benefit from services are not homebound by Medicare definition but may lack adequate transportation. OT programs described in the literature that demonstrate significant positive impact tend to be home based, which for insurance reimbursement requires being home bound (Padilla, 2011). This supports the need for a clinic-based OT intervention with a telehealth component directed at people with dementia and their care partners to reduce caregiver burden, increase quality of life of the dyad (the primary care partner and the care recipient), and promote aging in place. Telehealth is an emerging field and not currently well-utilized in occupational therapy but expected to be a growing practice trend. This intervention is well suited to translate to a fully telehealth-based model of care, with positive impact in rural areas.

Project Overview

Improving the Care Partner Experience: An Occupational Therapy Intervention for People with Dementia is a program designed to promote a care partner's ability to facilitate the care recipient's participation in desired activities, reducing caregiver burden and enhancing quality of life for both partners. The intervention utilizes the theory of Self-efficacy (Bandura, 1997) and the Model of Human Occupation (MOHO, Kielhofner, 2009). The development of self-efficacy for caregiving tasks such as facilitating everyday activities has been demonstrated to effectively reduce caregiver burden (Crellin, Orrell, McDermott, & Charlesworth, 2014; Semiatin & O'Conner, 2012). MOHO provides a framework for the intervention looking at the importance of how a person engages in

everyday activity, addressing motivation and performance capacity. MOHO posits that humans are occupational beings that derive meaning from purposeful engagement in activities. The distress of role reversal and changes in the ability to participate in daily occupations creates a crisis in occupational identity for both partners. As the care partner develops self-efficacy for the tasks required, the role of care partner will be integrated into the person's identity and create greater satisfaction with the new role.

The intervention outlined in this document uses a structured approach to treatment for the client and the care partner together. First, a structured interview with the dyad using a standardized tool, the Canadian Occupational Performance Measure (COPM), will identify desired occupations and daily tasks that are important for both the care partner and care recipient. The COPM will also identify the current deficits in performance that the client is experiencing. In this manner, goals will be collaboratively established for the course of treatment. Further evaluation will use evidenced based assessments to determine the person with dementia's current abilities to guide treatment activities and education for the care partner. Outcome measures will include a care partner quality of life assessment, a burden measure and a self-efficacy for caregiving measure.

After the evaluation is completed, the OT will use a template embedded within the intervention to create a customized educational plan for the care partner. This document will be carefully reviewed with the care partner at all subsequent visits. Each treatment visit will use the principles outlined in the theory of self-efficacy (Bandura, 1997) to practice those activities that were identified by the COPM as important.

Bandura (1997) found that a cycle of demonstration, guided practice, feedback, and finally, attempts to perform independently, foster a sense of self-efficacy that promotes persistence in a role or activity. In this case, the activity would be facilitating the client with dementia in participating in desired tasks. Modifying the task, adapting the environment and giving appropriate direction are the skills that are practiced with the OT and at home. The intervention outlines a specific format for each treatment session to promote self-efficacy using Bandura's proposed method.

In creating this intervention, the evidence was reviewed for current best practices. Two programs in particular, Care of Persons with Dementia in their Environment, or COPE (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010a) and Community Occupational Therapy in Dementia, or COTiD (Graff, Vernooij-Dassen, Thijssen, Dekker, Hoefnagels, & OldeRikkert, 2006) have been identified as models for care. Both programs teach care partners skills to facilitate occupational engagement and demonstrated significant reductions in caregiver burden with increases in quality of life (QoL) for both members of the dyad. These programs were administered in the home, so elements of both programs were adapted to be used effectively in the clinic or via telehealth. *Improving the Care Partner Experience* was designed to be clinic-based to address the homebound criteria that limits implementation in the home and to be ready to be used as a telehealth intervention as that area of practice grows. There is a growing body of evidence that telehealth programs can achieve significant effects for increasing self-efficacy and reducing caregiver burden (Jackson, Roberts, Wu, Ford & Doyle, 2016).

Key Findings

New Hampshire (NH) is a rural state with an aging population that needs access to effective dementia services. Given that caregiver burden is a primary factor in care partner stress and illness as well as nursing home placement, occupational therapy is uniquely suited to treat the occupational deficits and role crisis that leads to burden. The evidence supports reducing caregiver burden through the development of self-efficacy which in turn will reduce costs to society in care partner illness and institutionalization of people with dementia. This intervention is easily adapted to meet the needs of rural NH through telehealth means as insurance coverage and practice acts incorporate telehealth models into care delivery methods. The approximate cost to start this program at a facility is \$835.00.

Conclusion

Occupational therapy interventions that represent best practice are evidenced based and client centered. This project utilized the available evidence to create an intervention centered on improving the lives of people with dementia and their care partners. When implemented, the person with dementia will be more engaged in daily and desired occupations, and the care partner will experience a decrease in burden and an increase in quality of life. With these positive outcomes, *Improving the Care Partner Experience* will be a valuable tool for occupational therapists.

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**BOSTON
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**Improving the Care
Partner Experience:
An Occupational Therapy
Intervention for People with
Dementia**

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OTD candidate



The Problem:

- 5 million Americans are diagnosed with Alzheimer’s currently and 15 million people act as informal care partners (Alzheimer’s Association, 2017)
- Caregiver burden and decreased ability to engage in activities of daily living are leading causes for nursing home placement (Buhr & Clipp, 2006)
- Current evidence-based research demonstrates significant positive results with OT interventions in the home for clients with dementia. However, people with dementia who are not homebound do not have access to those services (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010a; Graff, Vernooij-Dassen, Thijssen, Dekker, Hoefnagels, & OldeRikkert, 2006).

Proposed Solution and Program Description:

- Improving the *Care Partner Experience* is a clinic-based OT manualized intervention for a person with dementia and their care partner.
- The program design fosters self-efficacy in the care partner to provide assistance to the care recipient in a way that encourages functional occupational engagement.
- By increasing self-efficacy, the care partner will experience decreased burden and both members of the dyad will experience increase quality of life (Crellin, Orrell, McDermott, & Charlesworth, 2014; Semiatin & O’Conner, 2012).
- The evaluation: a careful interview to identify the most desired occupations to engage in, whether self-care, leisure, or instrumental activities of daily living. Current challenges and abilities are assessed and a treatment plan is developed with written education for the care partner with customized suggestions.
- Over five visits targeted occupations are practiced with the dyad. Adapting the occupation, the environment and using appropriate communication are modeled, practiced and reviewed according to the principles of self-efficacy theory (Bandura, 1997)

Theoretical Model:

- Model of Human Occupation (Kielhofner, 2009) posits that people are motivated to participate in occupations that contribute to a meaningful occupational identity. This model describes a need to address changes in roles, habits and expectations.
- The Theory of Self-Efficacy (Bandura, 1997) proposes that people are motivated to engage in behaviors and roles when they feel effective and confident in their skills. Bandura's model of treatment for developing self-efficacy is utilized in the treatment visits of this intervention, and can be visualized in the following diagram:



Impact on Occupational Therapy (OT)

- While evidence of OT interventions for people with dementia exists, the rate at which these evidence based programs addressing occupations and activities of daily living are being translated into practice is alarmingly low (Gitlin, Marx, Stanley, & Hodgson, 2015).
- *Care Partner Experience* not only provides a structure for treatment of clients with dementia and their care partners, it is reproducible and evidence based.
- *Care Partner Experience* fills a practice gap both as an intervention for people with dementia as well as a clinic-based treatment program. Additionally, it can be implemented via telehealth, further expanding access to quality occupational therapy for all clients.

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Curriculum Vitae

