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This thesis examines the feasibility of the ASL for Active Living Program as an intervention for clinical practice among individuals with memory loss and/or aphasia with associated depression. It strives to answer the following questions: First will an eight session RT intervention impact on symptoms of depression in individuals with mild memory loss and aphasia? Second, will participation in this intervention change levels of self-esteem? Third, to what extent will the older adult participants be able to learn and retain finger-spelling and vocabulary taught? Lastly, will participants be satisfied with this type of intervention?

The first chapter reports the current trends of an aging society, as well as the increase in co-morbid disorders such as depression. The second chapter provides a thorough literature review which clearly identifies Mild Cognitive Impairment and Primary Progressive Aphasia as well as describes efficacy studies that provide the foundation for this study. The third chapter identifies the ARCS theory and model, and its contribution to providing a solid foundation for intervention development. The fourth chapter describes the research process and highlights the methods and procedures used throughout the research process. Chapter five describes the data using a mixed methods procedure to report the success of this intervention developmental study. Results indicate this is a feasible intervention for the field of recreation therapy for the treatment of depression for those with memory loss and/or aphasia.

A RECREATION THERAPY TWIST TO SIGN
LANGUAGE: AN INTERVENTION FOR
PRIMARY PROGRESSIVE
APHASIA

By

Angela Sardina

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To my mom, Sue, who has always been my rock. She taught me that hard work and perseverance will always pay off. Her love and support through this endeavor provided me with the encouragement I needed to “keep on trucking”.

To my father, Jorge, who passed away. Before his death he told me that “to get the best fruit you have to go out on a limb.” This taught me to take risks and work hard, and I will succeed in any and everything I put my mind to. It has helped me get to where I am today.

APPROVAL PAGE

This thesis has been approved by the following committee of the Faculty of The Graduate School at The University of North Carolina at Greensboro.

Committee Chair _____

Committee Members _____

Date of Acceptance by Committee

Date of Final Oral Examination

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TABLE OF CONTENTS

	Page
LIST OF TABLES	vii
LIST OF FIGURES	viii
CHAPTER	
I. INTRODUCTION AND STATEMENT OF THE PROBLEM	1
Introduction.....	1
Purpose of the Research Study	6
Need for the Study	7
Limitations	7
Measurement Tools Used in the Study	8
Research Questions.....	9
Definition of Key Terms.....	9
II. REVIEW OF THE LITERATURE	12
Overview of Mild Cognitive Impairment and Primary Progressive Aphasia	13
Dementia and Recreational Therapy.....	17
Recreational Therapy as a Treatment for Early-Stage Dementia	18
Treatment for Aphasia, PPA, and MCIwA.....	20
Depression and Dementia	23
Depression and Primary Progressive Aphasia	24
Sign Language and Aphasia.....	26
Conclusion	27
III. ATTENTION, RELEVANCE, CONFIDENCE, AND SATISFACTION MODEL	29
IV. METHODS AND PROCEDURES.....	33
Research Methods.....	33
Institutional Review Board	34
Research Site.....	34
Participants and Sampling.....	34
Assessments and Entrance Criteria.....	35
Competency of the Student Researcher	38
Procedures of ASL for Active Living.....	38
Data Analysis	41

V. TREATMENT OF THE DATA AND DISCUSSION	42
Group Data Results	44
Case Studies	49
Mrs. N	49
Mrs. T	52
Mrs. A	55
Mrs. B	57
Summary	60
Discussion	62
Implications	64
Limitations	65
Conclusion	66
REFERENCES	67
APPENDIX A. COVER LETTER	74
APPENDIX B. CONSENT FORM	76
APPENDIX C. DEMOGRAPHIC INFORMATION SHEET	80
APPENDIX D. ASL FOR ACTIVE LIVING ENGAGEMENT FORMS	83
APPENDIX E. PARTICIPANT SATISFACTION SURVEY	86
APPENDIX F. LESSON PLAN TABLE	88
APPENDIX G. SAMPLE PROTOCOLS	90
Beginning with the Ending Protocol	91
Sign Hangman Protocol	93
Whiteboard Scramble Protocol	95
APPENDIX H. EDUCATIONAL LESSON	97

LIST OF TABLES

	Page
Table 1. Signs of Depression in Older Adults	3
Table 2. Assessments	37
Table 3. Demographic Characteristics of the Sample (n=4).....	43
Table 4. PHQ-9 Pre- and Post-test Scores for Each Participant	44
Table 5. Participant Changes in Self-Esteem from Pre-test to Post-test.....	46
Table 6. Variables Indicating Satisfaction	48

LIST OF FIGURES

	Page
Figure 1. ARCS Model	32
Figure 2. Pre- to post-test scores on the PHQ-9 Depression Scale for all participants.....	45
Figure 3. Pre- to post-test scores on the Rosenberg Self-Esteem Scale for all participants.....	47
Figure 4. Satisfaction scores on a 1-10 scale as indicated by each participant on the Participant Satisfaction Survey.....	49

CHAPTER I

INTRODUCTION AND STATEMENT OF THE PROBLEM

Introduction

In the United States, we are seeing a rapid increase in the aging population as well as an overall greater life expectancy. In 1995, it was reported that the average life expectancy was approximately 75.9 years and by 2050 that number will drastically change as the new average will increase to approximately 82 years of age (Spirduso, Frances, & MacRae, 2005). It is expected that from 1995-2010 the 85+ age group will increase by 56%, compared to a 13% increase for individuals in the 65-84 age category (Spirduso et al. 2005). By 2030, 20% of the population will be 65 years of age or older, and in 2050, nearly 21.5 million will be 85 or older (Spirduso et al. 2005). These numbers represent a dramatic rise as baby-boomers begin to age and older adults continue to live longer.

Additionally, aging is often associated with natural changes that occur within the body such as graying of one's hair, loss of the ability to judge depth, as well as dry and wrinkled skin. Late-life changes can also result in un-natural problems such as depression. It is a common misconception that depression is normal in older adults, when in reality it is harmful and becoming too common to be ignored (Birren, Sloane, & Cohen, 1992). According to Cyr (2007), depression is a diagnosis that often goes undetected and therefore untreated due to various reasons such as: patient reluctance to identify emotional symptoms; potential stigmatization associated with diagnosis of depression; rushed or hurried clinicians missing the signs and symptoms of depression; as

well as a lack of knowledge regarding the condition and its prevalence among this population (Cyr, 2007). Also, because many doctors believe depression is normal in older adults they often do not order treatment for symptoms and often do not inform family members of their current condition. Furthermore, it has been identified that one-third of older adults experience symptoms of depression, and nearly five million fall within the clinically depressed range (Cyr, 2007).

The prevalence of depression throughout the United States is approximately one percent, and this number dramatically increases from 12-30% of individuals residing in long-term care facilities (Birrner & Vemuri, 2004). Due to high prevalence levels depressive symptoms must be recognized and treated among older people. This condition not only causes short-term problems, but can also be associated with long-term issues such as a compromised immune system, impaired wound healing, increase in the risk for cardiovascular disease, as well as contributes to the progression of breast cancer (Cyr, 2007). Nearly one-fourth of older adults will report their depressive symptoms whereas others may not, leaving symptoms of depression untreated (Cyr, 2007). Depressive symptoms may appear as a secondary disorder, especially upon the diagnosis of a progressive or terminal illness. Prevalence among depression and dementia is high due to development of symptoms such as: gradual memory loss and decreasing ability to perform routine daily living tasks, impaired judgment, disorientation, as well as personality changes (Burgener, Twigg, & Popovich, 2005). Signs and symptoms of depression in older adults are further elaborated upon in Table 1.

Table 1

Signs of Depression in Older Adults

1. Diagnoses of central nervous system disorder's (Alzheimer's disease, Parkinson's disease, and other dementias, multiple sclerosis
 2. Diagnosis of diabetes, hypothyroidism, macular degeneration
 3. Use of specific medications
 4. Alcohol abuse
 5. Increased dependency
 6. Frequent reports of pain or insomnia
 7. Headaches
 8. Changes in appetite or sleep habits
 9. Social isolation
 10. Increased gastrointestinal complaints
-

(Birrer & Vemuri, 2004; Cyr, 2007, p. 398)

Statistically, nearly 5.3 million individuals currently have dementia with this number primarily consisting of those aged 65 and older, yet 200,000 of the total number include younger onset Alzheimer's disease and other dementias (Alzheimer's Association, 2010). These facts show that dementia is a debilitating disorder which is growing more frequent within this population of individuals (Burgener et al. 2005). When dementia is mentioned, many individuals think of its most common form, Alzheimer's disease. Although the effects of depression among individuals with Alzheimer's disease has been highly studied and verified, it is also recently noted that depressive symptoms have been reported in patients with another specific form of dementia, Primary Progressive Aphasia.

Primary Progressive Aphasia (PPA) is defined as a "clinical dementia syndrome in which language functions decline over time while other cognitive and behavioral

domains such as memory, reasoning, and comportment remain relatively preserved for at least two years following symptom onset” (Medina & Weintraub, 2007, p. 153; Mesulam & Weintraub, 1992). This form of dementia is set apart from Alzheimer’s disease, as onset of symptoms are earlier in age and primarily focus on progressive loss of language, as opposed to amnesia and memory loss (Medina & Weintraub, 2007). PPA is often categorized within the frontotemporal dementias, which are becoming more increasingly recognized as they now comprise nearly 22% of individuals with neurodegenerative disorders (Medina & Weintraub, 2007). PPA is also a unique form of dementia as the language domain is the primary area affected, while other areas such as cognitive or behavioral functions remain in-tact from 2 – 14 years (Medina & Weintraub, 2007). This neurodegenerative disease often affects individuals within the young-old age group, more specifically those just under the age of 65 (Medina & Weintraub, 2007).

Furthermore, although research is limited, the question has arisen that because persons with PPA experience progressive language deficits in fluency, word-finding, and overall ability to communicate, they may be highly likely to have depression as a result of preserved memory, reasoning, and awareness of loss of language (Medina & Weintraub, 2007). In a study conducted by Medina and Weintraub (2007), it was found that a large number of individuals with PPA scored within the clinically depressed category and that depression was linked to social withdrawal and a decrease in physical and mental energy, due to an awareness of language deficits.

Our population as a whole is aging, and with age comes diseases, illnesses, and other challenges practitioners in the field of recreation therapy must address. With the fourth

leading cause of death being dementia-related illnesses and a growing number of individuals receiving diagnoses, it is important that practitioners begin to work with individuals at the early stages in order to decrease levels of depression and help them to improve their overall quality of life. Within Pearce, Clare, and Pistrang's (2002) works, it is proposed that "when people develop chronic illnesses, [i.e. dementia] their former social and personal identities and future plans are thrown into question because of the physical, social, psychological, and financial consequences of the illness" (p. 174). This alone could potentially be a predictor for depression within individuals at the early stages.

As a result, one potential means of reducing depression may be to intervene at the early stages utilizing recreation therapy treatments. One particular means of intervention for individuals with a diagnosis of PPA would be to provide an alternative means of communication. Due to a loss of verbal language, the possibility of teaching sign language to individuals diagnosed with PPA is a viable option for a secondary means of communication.

Limited research has been completed for individuals with aphasia and their ability to learn and communicate through sign language. Some research suggests that sign language may be an excellent intervention for those with aphasia (Anderson, Damasio, Damasio, Klima, Bellugi et al. 1992; Mesulam, 2003) although the research on this idea in relation to PPA is sparse. Because of the lack of published research addressing sign language for persons with PPA, there is room to further the body of knowledge in this area. As a result, highly interactive sign language courses that focus on teaching need-based and

leisure-based signs to individuals with PPA may be an effective means of treatment to reduce levels of depression and cause changes in self-esteem.

Purpose of the Research Study

Limited research exists that suggest any treatment approaches provide successful outcomes for individuals with a diagnosis of PPA. Therefore, the **primary objective** for this pilot intervention-development study was to determine the feasibility of a sign language intervention for the field of recreation therapy in its efforts to decrease symptoms of depression. Recreation therapy-based interventions were integrated into visual language activities to achieve the aforementioned goals while simultaneously increasing social, communication, and learning opportunities. A total of eight sessions were designed to increase in complexity from session-to-session as the knowledge base of the language continued to expand. Participant knowledge of vocabulary extended from need- to leisure-based sign language and finger-spelling. This intervention, ASL for Active Living, was developed as a classroom style sign language program by the student researcher in the summer of 2009.

The proposed intervention was based upon Keller's (1983) Attention, Relevance, Confidence, and Satisfaction (ARCS) motivation and learning theory. Within this model it is imperative to: First, gain the attention of participants through active and engaging interventions. Second, the therapist must increase relevance by developing interventions that address participant needs for coping skills, development in functional communication (understanding and conveying how to communicate through body language, posture, and gesturing to ensure less reliance on spoken language) and new

leisure opportunities. Third, the facilitator must provide experiences to increase levels of self-esteem. Lastly, the facilitator works to increase individual satisfaction through intrinsic and extrinsic rewards developed/obtained during intervention period.

Need for the Study

Based on preliminary evidence it has been suggested that individuals with PPA experience high levels of depression and are affected by social isolation (Medina & Weintraub, 2007). These levels of depression were identified when individuals with PPA were compared to their normal controls (Medina & Weintraub, 2007). Depressive symptoms most commonly resulted in social withdrawal, and lack of physical and mental energy, therefore creating emotional distress and impacting overall quality of life (Medina & Weintraub, 2007). This student researcher believed these symptoms could be reduced through highly interactive sign language lessons for community dwelling adults with mild to moderate PPA.

Limitations

The following were recognized as limitations existing within the study:

- (1) A small local convenience sample was utilized therefore decreasing generalizability to the larger population.
- (2) The effectiveness of the study may have been impacted by the amount of sessions that were held. Eight sessions may not be enough to learn and retain vocabulary taught.
- (3) Lack of long-term follow-up to assess sustainability of the interventions could inhibit how beneficial this intervention is, once dementia enters the latter stages. Individuals

with PPA or Mild Cognitive Impairment may experience a progressive degeneration, therefore inhibiting the retention and usability of sign language.

(4) The use of self-report outcome measures, which may rely on client's recall memory, may not be entirely accurate or reliable information. Answers may be misrepresented or individuals may not be able to recall memory of interventions, which could impact report of effectiveness intervention had on each individual during sessions.

Measurement Tools Used in the Study

Various aspects of an individual's life were assessed throughout this intervention study. The Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) was used to test cognition and thinking; The Cornell-Brown Scale (Ready, Ott, Grace, & Fernandez, 2002) indicated participants' current views on their Quality of Life over the past four weeks; Depression levels were indicated through the Patient Health Questionnaire (PHQ-9) (Kroenke & Spitzer, 2002); the Rosenberg Self-Esteem Scale (Rosenberg, 1965) measured current views of self; the Ohio Functional Battery Assessment – Section E. (Olssen, 1999) helped researchers to determine leisure motivation within an individual; the Boston Naming Test (BNT) (Kaplan, Goodglass, & Weintraub, 1983) measured language fluency and identified deficits in language to determine severity of impairment; and the Participant Engagement Rating assisted in identifying the level of in-session engagement for each individual.

Reliability and validity for the assessments mentioned can be found in Table 1 located within Chapter 4. The MMSE, PHQ-9, and the BNT scores were utilized as entrance criteria into the study to determine whether participants had memory changes, elevated

levels of depression, or aphasia. Once entrance criteria were met, the participants were assessed by the remaining measurement tools to determine baseline data. The in-session participation measures were used for each participant during every session, and were completed based on student researcher's observations. Participants were not assessed again until the conclusion of the interventions in which they received the PHQ-9, Rosenberg Self-esteem scale, and the Participant Satisfaction Survey.

Research Questions

1. Will an eight session RT intervention impact on symptoms of depression in individuals with mild memory loss and aphasia?
2. Will participation in this intervention change levels of self-esteem?
3. To what extent will the older adult participants be able to learn and retain finger-spelling and vocabulary taught?
4. Will participants be satisfied with this type of intervention?

Definition of Key Terms

Aggramatism: The presence of grammatical errors in speech, such as the omission or incorrect usage of articles (“cow jumped over moon”), prepositions (“dog walk bridge”) or verbs (“cat eated mouse”) (Medical Terms, 2009).

Articulate: a configuration of the vocal tract (the larynx and the pharyngeal, oral, and nasal cavities) resulting from the positioning of the mobile organs of the vocal tract (e.g., tongue) relative to other parts of the vocal tract that may be rigid (e.g., hard palate). This configuration modifies an airstream to produce the sounds of speech (Articulation, 2009).

Cognition: the process of perceiving, thinking, reasoning and analyzing (Glossary, 2009).

Frontal Lobe: The part of each hemisphere of the brain located behind the forehead that serves to regulate and mediate the higher intellectual functions. The frontal lobes have intricate connections to other areas of the brain. In the frontal lobes, we meld emotions, cognition, error detection, volition, a sense of self, and more to create our social brain (Medical Terms, 2009).

Frontotemporal Dementia: is an umbrella term for a diverse group of uncommon disorders that primarily affect the frontal and temporal lobes of the brain — the areas generally associated with personality, behavior, and language (Frontotemporal Dementia, 2009).

Functional Communication: The ability to receive or convey a message, regardless of the mode, to communicate effectively and independently in a given environment (What is, 2006).

Phonemic Paraphasias: Errors involving use of the incorrect phoneme (“ped” instead of “bed”) or transposition of a phoneme (“efelant” for “elephant”) (Medical Terms, 2009).

Primary Progressive Aphasia: is a clinical dementia syndrome in which language functions decline over time while other cognitive and behavioral domains such as memory, reasoning, and attitudes remain relatively preserved for at least 2 years following the onset of symptoms (Mesulam, 2003; Primary Progressive Aphasia, n.d.; Medina & Weintraub, 2007).

Quality of Life: Referring to an overall sense of well-being with a strong relation to a person's health perceptions and ability to function. On a larger scale, quality of life can be viewed as including all aspects of community life that have a direct and quantifiable influence on the physical and mental health of its members (Healthy Places, 2009).

Recreation Therapy: Therapy ordered by a physician that provides therapeutic stimulation beyond the general activity program in a facility and physician ordered services which must include the frequency, duration, and scope of treatment (CMS, 2009).

Temporal Lobe: The lobe of the cerebral hemisphere located down on the side of the brain near the ears. The temporal lobe contains the auditory cortex which is responsible for hearing, language comprehension and memory (Medical Terms, 2009).

CHAPTER II

REVIEW OF THE LITERATURE

In a review of the literature, there were no previous studies conducted which taught sign language to individuals with Primary Progressive Aphasia or Mild Cognitive Impairment (MCI) with aphasia (MCIwA). In addition there was no literature for therapeutic recreation interventions for these conditions. A computer search among various databases such as ProQuest, PubMed, and Google Scholar provided general information and studies regarding PPA and MCIwA. Minimal information regarding psychosocial treatments for this population existed that was relevant to this current research study.

This research was conducted to determine whether individuals with mild to moderate PPA or MCIwA could potentially increase social engagement with others through learning and practice of a visual language, which may in turn decrease levels of depression. Due to the lack of research regarding this particular intervention of sign language for those with PPA or MCIwA, this literature review is broken down into various segments that will consist of an overview of MCI and PPA; dementia and recreation therapy; recreation therapy as a treatment for early-stage dementia; treatment for aphasia, PPA, and MCIwA; depression and dementia; depression and PPA; and sign language and aphasia.

Overview of Mild Cognitive Impairment and Primary Progressive Aphasia

Mild Cognitive Impairment is a condition where individuals experience problems with memory, language, or other mental functions that may be noticeable enough to other individuals but not serious enough to interrupt daily life functioning (Torpy, Lynn, & Glass, 2009). MCI can be identified through neurological exams, mental status exams, lab tests, and brain scans (Torpy et al. 2009). This disorder may primarily affect areas of thoughts and actions such as language, attention, reasoning, judgment, reading and writing, with the more prominent symptom of memory loss. Research shows that MCI affects an average of 20 percent of older adults with memory and cognitive impairment but no formal diagnosis of a dementia (DeCarli, 2003).

Mild cognitive impairment causes changes to the brain that are similar to Alzheimer's disease (AD), with the primary difference of more mild cases specifically in the initial stages. Research currently shows that individuals diagnosed with MCI are at greater risk for developing AD after a few years, especially when the prominent symptom is memory loss (DeCarli, 2003). Memory loss and other symptoms associated with MCI may be attributed to plaques (abnormal clumps of proteins called beta amyloid), tangles (abnormal clumps of a protein called Tau), shrinkage of the hippocampus (an area of the brain that is crucial to the memory process), strokes, and Lewy Bodies (abnormal clumps of proteins often associated with Parkinson's disease) (Small et al. 2006).

Although not all cases will progress into Alzheimer's disease, it is important to note there is currently no treatment for MCI that is shown to be effective (DeCarli, 2003). Medicinal treatments are currently available but have not proven to be effective for long-

term usage; they may also lead to adverse side effects. Additionally, individuals may experience depression, irritability, anxiety, aggression, and apathy as co-morbid neuropsychiatric symptoms (DeCarli, 2003; Morris & Cummings, 2005).

Mesulam, Grossman, Hillis, Kertesz, and Weintraub (2003) describe PPA as a language-based form of dementia, which has unique characteristics setting it apart from typical forms of dementia. Mesulam (2007) notes that “The diagnosis of primary progressive aphasia (PPA) is made in any patient in whom a language impairment (*aphasia*), caused by a neurodegenerative disease (*progressive*), constitutes the most salient aspect of the clinical picture (*primary*)” (p. S8).

The average age of onset of PPA is approximately 50 years of age, but can vary between 40 and 70 years of age. Unlike many individuals with a dementia subtype, PPA is unique in its clinical findings, as its primary symptoms present in the form of word-finding difficulties, speech abnormalities, difficulties with object naming, syntax, or comprehension, and/or deterioration in one’s ability to spell (Mesulam, 2007; Mesulam et al. 2003). This form of dementia is diagnosed when brain imaging reveal no specific lesions, and when memory, visuospatial abilities, and behaviors remain relatively stable resulting in a steady but gradual and progressive loss of spoken language is seen as the primary symptom during the first two years of the disease (Mesulam, 2003; Mesulam, Grossman, Hillis, Kertesz, & Weintraub, 2003). PPA is not usually diagnosed until other options and diagnoses are exhausted (Mesulam et al. 2003). PPA is a language-based dementia, just as Alzheimer’s is a memory-based dementia (Mesulam, 2007). Because it affects each individual differently, some may present with word-finding difficulties, some

may be incapable of comprehending written or spoken words, while others are unable to name specific objects (Mesulam et al. 2003).

Additionally, PPA may also present as the fluent (normal articulation and flow, with correct amount of words per statement) or non-fluent types (difficulty in word production, sound errors in speech, inappropriate word order, etc.) (Mesulam et al. 2003). Mesulam and colleagues (2003) describe a common sign of PPA as the development of anomia (the inability to find the correct word). From anomia individuals may progress into the aggramatism phase (inappropriate word order), and incorrect usage of small grammatical words (Clark, Charuvastra, Miller, Shapira, & Mendez, 2004; Mesulam et al. 2003).

Other cases may present with anomia which develops into a progressive loss of word-finding abilities without progression into other areas. Regardless, individuals who present with prominent symptoms of aggramatism tend to be non-fluent and have adequate comprehensive abilities, while those who are fluent tend to have greater difficulties or impairment in comprehension (Mesulam et al. 2003). Because PPA is a language-based dementia individuals may not experience secondary progressive symptoms (cognitive decline, memory loss, etc) until two years after the onset of language symptoms, while others may remain relatively intact for 10-14 years. The average rate at which secondary symptoms present themselves are five years after initial onset and are shown among 50% of individuals diagnosed (Duffy & McNeil, 2008).

Mesulam (2003) indicates that the language network is located primarily on the left side of the brain within the frontal, and tempoparietal regions, inhabiting Broca's

(containing the motor speech areas and controls movements of the tongue, lips, and vocal cords) and Wernicke's areas (comprehends written and spoken word in the language process). PPA has been shown to result from atrophy within the frontal and tempoparietal regions, electroencephalographic slowing (decrease in electrical activity within the brain), decreased amount of blood flow to these regions of the brain (as shown by single-photon-emission computed tomography, or SPECT), and decreased amounts of glucose use (displayed by the positron-emission tomography, or PET scan) (Mesulam, 2003). Eventually, the progressive neurodegeneration will overrun much of the cerebral cortex and lead to the development of additional deficits (Mesulam, 2007).

Experts caution against confusing PPA, AD, and frontotemporal dementias (FTD's), as the loss of language within AD and FTD's present with underlying memory loss and behavioral impairments. This information and distinction between the dementia subtypes allows for clear identification of the boundaries of PPA, and how to distinguish it among other conditions presenting with comparable symptoms.

Understanding the diagnostic criteria is imperative to comprehending the parameters of this condition. Mesulam (2003) notes that some patients with PPA continue to maintain participation and can become more active in recreational endeavors centered-around their leisure interests. Because individuals with PPA maintain their activities of daily living late into the disease and remain actively engaged in recreational activities, it suggests that a recreation therapy-based sign language intervention may be successful within this population.

Dementia and Recreational Therapy

Approximately five million individuals with varying forms of dementia reside within residential communities and currently there are limited available programs for individuals within their early stages (Buettner, 2006; Buettner & Fitzsimmons, 2003). In most cases, immediately after diagnosis, individuals are provided with cholinesterase inhibitors for relief of cognitive symptoms, although this does not prevent the disease from progressing into the later stages (Buettner, 2006; Fitzsimmons & Buettner, 2003; Mesulam, 2007). It may also increase the chances of injuries and/or falls, problems with mobility and nutrition, increase risk for depression, delirium, or reactions between medications, as well as complications associated with communication and activities of daily living (Buettner & Fitzsimmons, 2003). These cholinesterase inhibitors do not appear to diminish the high risk for institutionalization, poorer health outcomes, and overall decline in quality of life (Buettner, 2006).

According to Buettner (2006) “A lack of evidence-based therapy programs for persons with mild or moderate dementia accounts for many negative health outcomes, such as poor emotional functioning, decline in physical functioning, social isolation, and risk of behavioral symptoms” (p. 42). Therefore, incorporating the appropriate cognitive, physical, and psychosocial interventions is important in slowing down associated symptoms of dementia (Buettner, 2006). Studies have identified that individuals with a diagnosis of dementia spent much of their time with limited cognitive or physical stimulation (Logsdon, 2000; Buettner & Fitzsimmons, 2006).

Recreational Therapy as a Treatment for Early-Stage Dementia

Buettner's (2006) Florida demonstration project was conducted to describe the importance of developing community-based interventions for individuals diagnosed with varying forms of dementia and to identify key components necessary to maintain quality of life. It appears crucial to implement community programs that can be established and conducted in a dignified way to meet the unmet needs for stimulation and therapy for associated dementia symptoms (Buettner, 2006). Buettner notes that,

Community-based programs designed to change health behaviors and build on client strengths hold promise in terms of management strategies for symptoms of excessive disability, anxiety, poor self-efficacy, behavioral symptoms, and more rapid than normal cognitive decline, because they fill unoccupied time with carefully planned stimulation; provide hope, coping strategies, and peer support; and promote physical and mental activity. (p. 43)

The established program conducted within the demonstration project consisted of a community control that was recommended to maintain healthy cognitive, physical, and social living over a course of 6-12 months, while the treatment group was provided a choice of therapeutic interventions that stretched across a continuum of care. The results showed that there were significant improvements within the continuum of care group in cognition, quality of life, and depression levels. This study provides evidence for the field of recreation therapy to provide effective interventions for individuals with early stage dementia that still reside in the community.

Buettner and Fitzsimmons (2006) established a Recreation Club in Port Charlotte, Florida for individuals with varying types and stages of dementia. The Recreation Club provided a stigma-free alternative to adult day care. This four hour program utilized

exercise, relaxation techniques, cognitive stimulation, therapeutic cooking, and psychosocial games to increase overall quality of life and maintain function for individuals with dementia. The primary goal of this type of program was to prevent or delay institutionalization, and to provide respite and/or support to family members and caregivers. Feedback from Recreation Club participants showed 90% of participants felt their health had improved since initial attendance began, 97% of participants developed three or more close friends from attending, and 92% felt they developed new leisure interests. In addition, many felt the program led to more opportunities for other areas of participation within the community (Buettner & Fitzsimmons, 2006).

Buettner and Fitzsimmons (2003, 2009) completed two additional studies on health promotion that were successful in determining that individuals in the early stages of dementia could still learn new information. It was initially suggested that individuals with dementia would have difficulty learning and understanding new information. However, researchers now know that for information to be stored it must be moved from short-term to long-term memory, which is typically done when it is both relevant and important to the individual.

The first research project was a 10-week study that examined teaching individuals with AD diagnoses within a university setting about the disease process and how to make the necessary adjustments to current ways of living (Buettner & Fitzsimmons, 2003). The study utilized various teaching methods, and was structured as a college course to promote learning, socialization, and self-efficacy to relieve stress levels and depression.

The second larger study (n=89) tested a 12-week health promotion course for older adults with early-stage dementia in four locations (Buettner & Fitzsimmons, 2009). In a quasi-experimental design, participants were assigned by site to intervention group or control group and evaluated at two time points. Mini-Mental State Examination scores, Geriatric Depression Scale scores, health behaviors, plus several measures of psychological well-being were used in this study. In the independent samples *t*-test analysis, significant positive change was found from pretest to posttest for the treatment group on cognition and depression. Additionally, a chi square analysis found several significant positive differences in health behaviors for the treatment group. These researchers indicated new information can be learned to improve knowledge and understanding, participation in this recreational-therapy learning based course could positively impact changes in lifestyle, and increases in socialization, self-efficacy, and self esteem can be established.

The aforementioned studies provide supporting evidence that individuals with PPA, early stage dementia, or MCIwA have the capabilities of learning and successfully participating in a recreation-therapy based program to learn need- and leisure-based sign language. The information supports the notion that if the intervention is conducted correctly and aims specifically at the needs of the individual, learning and long-term retention of signs may be possible.

Treatment for Aphasia, PPA, and MCIwA

Although there is evidence to support recreational therapy interventions for persons with mild memory impairments no studies were reported specific to the treatment of

PPA. Lack of clearly-presented research exists in the area of treatment for PPA. The literature that does exist focuses on the treatment for aphasia, not the secondary affects as they impact on the mood and quality of life of an individual. Aphasia in general may be related to other factors not associated with PPA, such as stroke, brain injury, or tumor (Herrmann, 1997).

Croot, Nickels, Laurence, and Manning (2009) suggested progressive language impairments may benefit from treatments currently available for stroke-related aphasias. Despite the differences in the nature of the conditions, adaptations can be made to treatment goals and interventions to specifically meet the needs of the progressive aphasias, i.e. PPA. Specific therapies must focus on slowing of the deterioration, as opposed to improving one's current situation (Croot et al. 2009). According to Herrmann (1997) speech and language therapy are the predominant methods of treatment for people with aphasia. Mesulam (2007) added that different types of treatments are beneficial for different people. In some cases, speech therapy is beneficial whereas in other cases, individuals may find a level of success with communication enhancement devices, or acquiring basic levels of sign language (Mesulam, 2007).

Research conducted by Amici, Gorno-Tempini, Ogar, Dronkers, and Miller (2006) further supports the idea that there is currently a lack of treatment options available within the PPA population. In a study that examines PPA and its variants, the authors highlight that treatment options are lacking, noting one particular efficacious treatment for this population has not been identified. The authors primarily identified several medicinal options that have been tried for this population; although to date most have

been ineffective (Mesulam, 2007). Cholinesterase inhibitors, which are often prescribed in the treatment of AD, proved to be ineffective and showed an increase in negative behavioral symptoms for clients with PPA (Mesulam, 2007). Selective Serotonin Reuptake Inhibitors (SSRI's or antidepressants) and atypical neuroleptics (antipsychotics or mood stabilizers) have been used to control behavior, although they do not improve language symptoms (Amici et al. 2006).

Within the literature, there has been a shift of importance to utilizing psychosocial therapies for persons with aphasia as other treatments may only be considered as a temporary fix (Hermann, 1997; Mesulam, 2007). Types of psychosocial treatments include support groups or educational programs for both patients and families (Mesulam, 2007). Speech and language therapy models and evaluation procedures have been elaborately developed but for the most part, psychosocial treatment models and evaluations consist of fragmented and inconsistent data reporting therapeutic procedures (Hermann, 1997). This lack of psychosocial treatment not only impact on the individual with aphasia, but it also affects the families (Hermann, 1997). Therapeutic procedures which take both the individual with aphasia and his or her family into consideration are rarely applied.

Both of these studies greatly support the need for psychosocial interventions for individuals diagnosed with PPA. Limited evidence exists for medicinal methods of treatment, and psychosocial therapies are essentially non-existent. The body of knowledge is relatively small and therefore the development of treatment options is needed.

Depression and Dementia

Depression is commonly found as a co-morbid disorder to dementia and its sub-types. Mild to moderate depression can be identified in up to 77% of community-dwelling older adults with a dementia diagnosis and is the most common mood disorder (Fitzsimmons & Buettner, 2002). Depression can create the risk for functional decline, excess mortality, overall decreased quality of life, and may increase the rate at which people would need institutionalization (Appleby, Roy, Valenti, & Lee, 2007; Buettner, Fitzsimmons, & Dudley, in press; Fitzsimmons & Buettner, 2002; Netuveli & Blane, 2008; Starkstein & Mizrahi, 2006). The link between the body and the mind has shown that individuals' moods and attitudes often affect various body systems, therefore it is important to address depression with the appropriate therapies and interventions (Buettner & Fitzsimmons, 2003). The common form of treatment is pharmacological such as anti-depressants, which may often cause adverse side effects (Fitzsimmons & Buettner, 2002; Greenberg, 2007). Although anti-depressants have become safer and are often effective for community-dwelling older adults, the most effective treatment is to incorporate medicinal strategies and appropriate psychosocial therapies (Fitzsimmons & Buettner, 2002).

Furthermore, recreational therapy has become increasingly utilized for both community-dwelling older adults and those in long-term care who have depression. Fitzsimmons and Buettner (2002) completed a clinical trial of therapy biking to determine if this recreational therapy intervention had an effect on individuals with depression who resided in a long term care facility. The results showed that older adults (n=39) who participated in the intervention showed a significant decline in overall levels

of depression while those who were in the control group did not. Wheel-chair biking was utilized in two other studies, all providing highly significant changes in depression among individuals in long-term care facilities (Buettner & Fitzsimmons, 2002; Fitzsimmons, 2001).

Another study that provides a secondary analysis of tailored recreational therapy for behaviors in dementia indicates the importance of depression in the outcome (Buettner et al. in press). Depression serves as a moderator in the treatment of behaviors and significantly influences the approach that should be used for agitation and passivity (Buettner et al. in press). The authors identify that for people with dementia and depression a tailored intervention during passive periods alleviates agitation. Depressive symptoms can play a significant role in behavior of those who are left untreated, indicating a crucial need for holistic assessment and treatment approaches.

As a result, the information and studies presented above provide supportive evidence that recreation therapy interventions that are accurately tailored to individual needs can be effective in the treatment of depression. Because previous research has shown that depressive levels are higher among individuals with PPA it can be noted that the development of appropriate recreation therapy interventions will help alleviate symptoms of depression resulting from the primary condition.

Depression and Primary Progressive Aphasia

Similarly, it has been suggested by Medina and Weintraub (2007) that the majority of individuals diagnosed with PPA may also present with symptoms of depression. The onset of symptoms in PPA most commonly present in those younger than 65, when

individuals may be in the middle of their careers, when children are in young adulthood, or at a general stage in life when dementia is rare. Because language is primarily affected there is a general awareness by patients and family of the loss of language over time. These researchers base their study on the theory that many individuals may develop frustration and depression as a result of their remaining awareness of the loss of language that is occurring, despite the fact that their other cognitive processes remain relatively intact (Medina & Weintraub, 2007; Mesulam, 2003). These authors also identified the potential need for further research on depression in PPA, as it has been identified that 20-25% of people diagnosed with AD experience depression (Lyketsos, 2001; Medina & Weintraub, 2007).

Robinson and Benson (1981) examined the occurrence and severity of mood changes for individuals with post-stroke aphasia. Researchers used four verbal and nonverbal examinations which concluded that approximately 50% of patients experienced depression (Robinson & Benson, 1981). Those with the non-fluent aphasia exhibited the greatest severity of depression, accounting for 71% opposed to those with fluent aphasia which accounted for 44%. The closest research identified was that of semantic dementia, which presents similarly as a PPA subtype, and concluded that 28% of their participants experienced depression (Thompson, Patterson, & Hodges, 2003).

Due to lack of research, Medina and Weintraub (2007) developed a study with PPA (n=61), to determine fluency, cognitive abilities, and levels of depression. The results were then compared to normal controls (participants without PPA or known cognitive deficits) to determine levels of depression. Findings indicate that: 1. Although

participants were not within the clinically depressed range, they did show more symptoms of depression when compared to normal controls; 2. The severity of the language impairment often reflected the severity of the depression; and 3. Depression was associated with social withdrawal and a decrease or lack of energy, with single items indicating that these participants were aware of cognitive and linguistic decline. The researchers also note that the emotional impact of PPA requires a greater amount of attention. Finally, these findings further support the notion that development of interdisciplinary treatment programs may help with psychosocial adjustment to the PPA diagnosis (Medina & Weintraub, 2007).

Sign Language and Aphasia

Christopoulou and Bonvillian (1985) noted that within the literature manual communication, or that of American Sign Language (ASL) has sparked interest for those with aphasia for several reasons. First, there is a general understanding that ASL is an autonomous language. Second, there has been substantial success in teaching sign language to those with autism and nonhuman primates. Lastly, it highlights a potential separation between brain and language. Some argue that verbal and nonverbal methods of communication form along different pathways making them independent of each other (Christopoulou & Bonvillian, 1985). As a result, utilizing visual languages may in fact be an effective technique for individuals with aphasia (Christopoulou & Bonvillian, 1985).

Anderson, Damasio, Damasio, Klima, Bellugi, and Brandt (1992) conducted a study that effectively evaluated a sign language intervention for individuals with severe aphasia due to stroke or head injury. It is important to note the authors defined American Sign

Language (ASL) as “an autonomous language with organizational principles similar to those of English and other auditory-vocal languages, but with a mode of transmission and with linguistic mechanisms that have evolved within the framework of a visual-gestural symbolic system” (1992, p. 329). This study included three hearing individuals with severe aphasia and no prior knowledge of sign language, two participants with damage to the left hemisphere, and one patient with damage to all temporal regions. All participants were taught 100 signs comprised of various parts of speech, emphasizing words that directly correlated to everyday activities. At the end of the intervention period all individuals were tested on the signs and all received near 100 percent retention with the exception of the individual with severe temporal damage who still received a score of 81 percent. Overall this study was effective in demonstrating that individuals with severe aphasia successfully learned and executed signs, despite their inability to communicate spoken language.

Conclusion

A review of the literature suggests that dementia is a prevalent condition, with high incidence for co-morbid depression. Pharmacological and non-pharmacological interventions have been successfully used to treat depression. However, the current treatment or intervention options for PPA and MCIwA, are understudied and poorly understood. It is timely and appropriate to develop a recreational therapy intervention program to assist individuals with coping with their loss of language that targets the problem of depression. The current program being studied will determine whether interactive sign language lessons have an impact on individuals with PPA or MCIwA.

Because individuals with PPA and MCIwA can still transition short-term memory into long-term memory, it is assumed that the development of a second, visual language will not only help to develop another means of communication but to create social opportunities in an engaging environment to help relieve symptoms of depression.

CHAPTER III

ATTENTION, RELEVANCE, CONFIDENCE, AND SATISFACTION MODEL

The need for identifying a theory associated with the research is vital for providing the foundation and backbone for the study. According to Fawcett and Downs (1986), “theories provide structures for the interpretation of individual’s behavior and of situations and events” (p. 2). It allows one to look at the situation or event and understand why and how something happens. Theories are designed to and should reflect the phenomena of interest to certain disciplines, therefore allowing it to not only explain the phenomena but also accurately predict something about the experience as well as explain its occurrence (Fawcett & Downs, 1986).

ASL for Active Living utilized the Attention, Relevance, Confidence, and Satisfaction model, developed by Keller (1983; 2000). The ARCS Motivation and Learning theory includes four concepts integrated into a systematic theory, including; attention, relevance, confidence, and satisfaction (Keller, 2000), and is what this study is founded upon. These four concepts are designed primarily to form the foundation of achieving full learner motivation (Keller, 2000). In this case it is utilized to identify the most efficient methods to teach participants need- and leisure-based sign language, with the best chances for retention of the signs, decreases in depression, and to evaluate the motivation to learn the language.

The first concept that the model addresses is that of **attention**. It suggests that within a program session, the facilitator must first gain the participant's attention. Keller (2000) notes that attention can be gained through unexpected events, as well as by triggering a deeper level of curiosity within the individual. Once attention has been gained it is therefore important to incorporate a variety of methods into the research. Within the ASL for Active Living intervention, attention was gained through the introduction of the day's session. For instance during session one, individuals had to introduce one activity they enjoy to the group without using voice, sounds, or verbal cues. Group members had to guess the activity based on the gesturing. After a brief lesson introducing the key elements of sign language, the participants were then asked to choose another activity and attempt to act it out again. The awareness of how to portray non-spoken language through the body increased dramatically.

After attention has been gained, the facilitator must provide **relevant** material that is deemed valuable to the participant (Keller, 2000). Keller reported "Even if curiosity is aroused, motivation is lost if the content has no perceived value to the [participant]" (p. 2). Therefore for each session developed for this project, there is an educational component that incorporates the appropriate information to meet the participant's needs (i.e., the importance of body language, gesturing, mimicking, and facial expressions in sign language and communication; or learning about the importance of emotions and how to convey them through the body).

According to the ARCS Model, once attention and relevance to the participant have been established, it is imperative for the facilitator to create a fail-safe environment in

which the participants gain **self-confidence** through continual success. Additionally it is crucial that participants attribute successes to personal effort, as opposed to external reasons such as luck, or being inadequately challenged (Keller, 2000). As a result, all individuals that participated did so in an environment in which failure was nearly impossible. Programs and activities were adapted to meet the group- and individual- needs. Participants also attended with a partner with the understanding that it would provide moral support, build confidence, and to allow individuals to communicate and practice with someone outside of sessions.

The last concept to this model is that of satisfaction. The **satisfaction** component is derived on intrinsic and extrinsic rewards that are established by the facilitator as well as the participant. For this research study, all participants received a certificate upon completion of the program highlighting extrinsic motivation. Intrinsic motivation was derived from personal accomplishment and desire to learn. Satisfaction was gained by incorporating extrinsic and intrinsic motivation for this particular project. The following concepts can be identified in visual form in figure 1 that follows.

Identifying the appropriate theory was crucial to developing a sound study, in which all aspects of the phenomena that occurred could be accurately pin-pointed and explained. The theory chosen assisted in the further establishment of the session details. Chapter four details the methods and procedures used to complete this study and how they aligned with the ARCS theory.

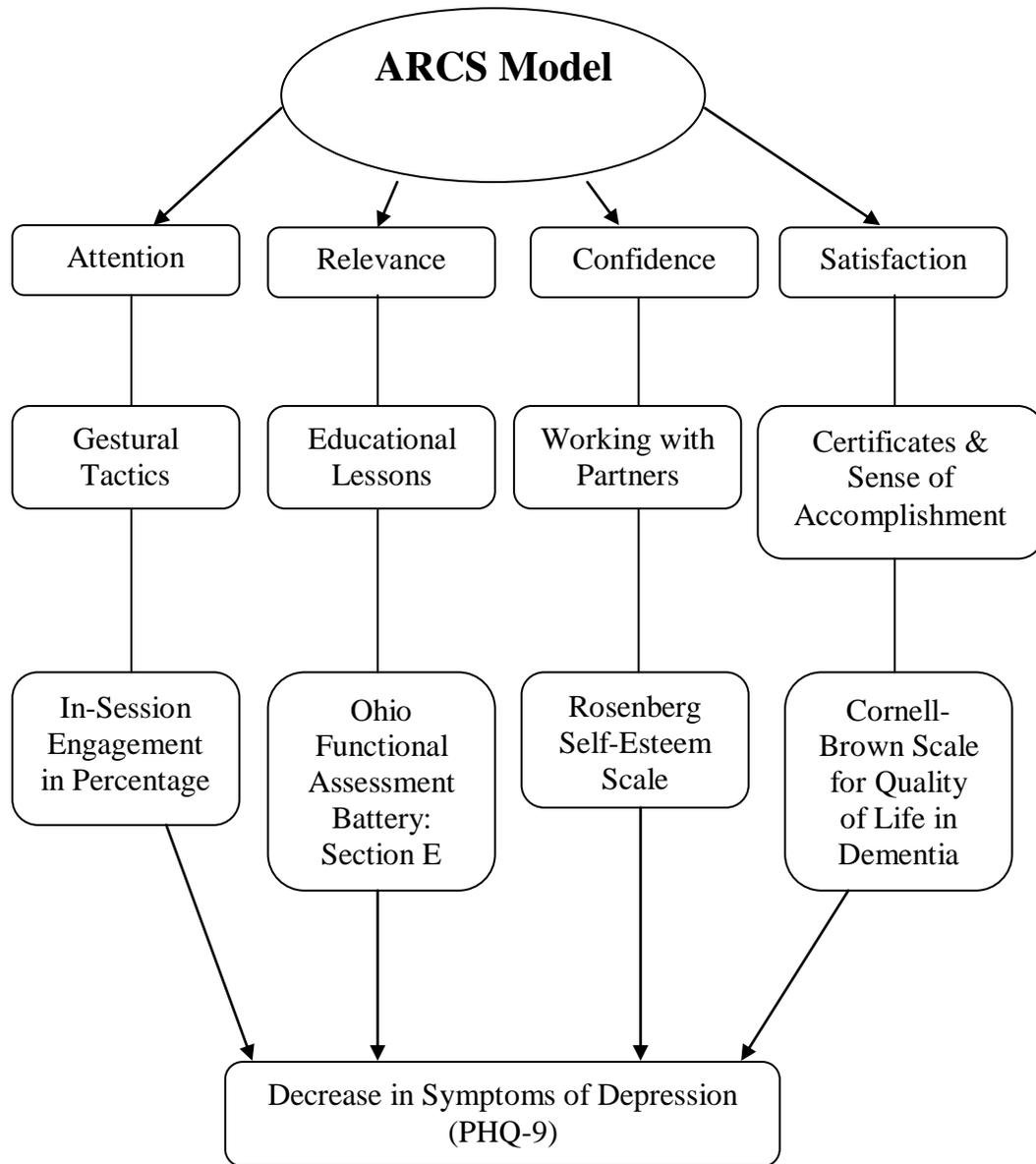


Figure 1: ARCS Model. This version of the ARCS was developed by the student researcher to represent the processes of the recreational therapy intervention. All process are designed to lead to a decrease or elimination of depressive symptoms, which evaluated through the PHQ-9.

CHAPTER IV

METHODS AND PROCEDURES

The purpose of this study was to determine whether this program designed for persons with mild to moderate PPA or MCIwA was a feasible intervention for the field of recreation therapy to aid in the reduction of depression. The project examined depression as a primary treatment outcome although it also evaluated whether a change in self-esteem was possible. Conducting this pilot study allowed for identification of adaptations necessary for various cognitive deficits as well as components that may not work or may need adapting to increase success.

Research Methods

This intervention was developed and piloted as a classroom style sign language program by the student researcher in the summer of 2009. The study used a pre-experimental design with pre- and post-testing of four participants over the course of eight sessions. Pre-experimental designs are so named because they follow basic experimental steps but fail to include a control group. In other words, a single group is often studied but no comparison between an equivalent non-treatment group is made. As a result, each participant's progress was identified separately, as if in case-study form, allowing for progress to be identified on an individual level. This study is primarily an intervention-development study of a new intervention for this population. The pre-experimental design method allowed the student researcher to develop an intervention

and test the initial effectiveness before comparing it to other treatment methods used in the field of Recreation Therapy.

Institutional Review Board

The research project protocol was submitted to The University of North Carolina at Greensboro Institutional Review Board in December of 2009. The revised protocol was approved on February 11, 2010.

Research Site

The Continuing Care Retirement Community (CCRC) in which the study was held was accredited by the Continuing Care Accreditation Commission (CCAC) of the American Association of Homes and Services for the Aging (AAHSA). Accreditation is a voluntary process that measures continuing care retirement communities against stringent national standards for excellence. The CCRC community meets or exceeds accreditation standards in all areas of inquiry, governance, resident life, finance, and health care. Over 400 residents over the age of 65 live at this CCRC community, which is located in North Carolina.

Participants and Sampling

There was a total of four research participants included in the study. Because each participant was encouraged to participate with another individual, there were six people in attendance per session although only the data for four participants was collected. All research participants lived in the CCRC community and were recommended by CCRC recreation therapy staff, nursing, or by a speech language pathologist as potential participants. All participants had pre-existing memory complaints and indications of

aphasia. All four participants were white females between the ages of 80 and 88, residing in either independent or assisted living at the CCRC community. Three of four participants displayed a level of depression or indicators of depressive symptoms present at baseline.

Initial contact was established by phone, and a follow-up meeting was set up to provide the potential participant with information regarding the study. Interested participants were set up with an appointment time for baseline testing to establish whether entrance criteria were met. Before any assessments were completed, the participants signed the consent form approved by the Institutional Review Board from The University of North Carolina at Greensboro. Due to lack of a control group, the sample was chosen based on recommendation of CCRC staff and therefore was not randomized in any way. Because this is a preliminary pilot-study to test the components of the intervention, a larger randomized control trial would need to take place for the findings to be generalizable.

Assessments and Entrance Criteria

The entrance criteria for the study required that participants have a diagnosis of PPA, or Mild Cognitive Impairment with aphasia. Also included within these parameters were individuals who indicated memory loss, depression, and/or aphasia to some extent. The minimum required score on the MMSE was >15. Additionally, participants had to have a diagnosis of depression, complaints of social loss, or indicate elevated levels in depressive symptoms on the PHQ-9. Before the administration of the assessments, all participants signed the approved consent form from the UNCG Institutional Review

Board. After consent was received the participants were assessed using the Mini-Mental State Examination (MMSE), Cornell Brown Quality of Life Scale, The Patient Health Questionnaire (PHQ-9), Participant Engagement Rating, Rosenberg Self-Esteem Scale, Ohio Functional Battery Assessment, and the Boston Naming Test.

The MMSE was used to indicate the cognitive level of functioning for each participant to ensure that they were able to fully participate in the intervention sessions. For participants with PPA, they may experience difficulty on the MMSE as it is a verbal test. Some participants may receive a lower score not due to cognition or memory levels, but based more on deficits in speech. Therefore, a lower MMSE score of 15 was indicated for this study to accommodate language deficits which impacted on the score itself. On the PHQ-9 a score of five or higher indicated the participant is experiencing at least a mild form of depression or depressive symptoms. The Boston Naming Test was also important and used within the entrance criteria to determine whether language impairments existed and to indicate the extent of severity. Table 2 provides further information regarding the assessments and provides validity and reliability indicators for each tool.

Table 2

Assessments

<u>Variables</u>	<u>Measurement Tools</u>	<u>Reliability and Validity</u>
Cognition	(MMSE)	Consists of 11 questions or tasks (r>0.89)
Quality of Life	Cornell-Brown QOL	Interrater reliability (intraclass r = 0.90) and internal consistency reliability (Cronbach alpha = 0.81)
Depression	PHQ-9	Sensitivity of 88 percent and a specificity of 88 percent for major depression.
In-Session Engagement	Participant Engagement Rating	Observed: engagement %, time, participation type (active, passive, refused), difficulty in performing activity, interaction with others.
Self-Esteem Scale	Rosenberg Self-Esteem Scale	Test/re-test reliability is 73.7%. Validity reported at .68-.99
Leisure Motivation	Ohio Functional Assessment Battery	It has reported inter-rater reliability and validity
Fluency	Boston Naming Test	Thirty item assessment has strong test-retest reliability and good validity (reliability alpha = .90).

Participants were assessed before the start of the first intervention session, with all assessments previously mentioned being administered to establish a baseline. The second round of assessments occurred at the conclusion of the intervention, and these assessments included the Rosenberg Self-Esteem Scale, the PHQ-9 for depression, and

the Participant Satisfaction Survey. The Participant Engagement Rating was conducted at the end of each session by of the student researcher.

Competency of the Student Researcher

The student researcher was formally trained to use all the indicated assessments. A Licensed Recreational Therapist/Certified Therapeutic Recreation Specialist trained the student researcher to utilize the Recreational Therapy based assessments, and a Speech Language Pathologist and Doctoral Student of Speech Language Pathology trained the student researcher to administer the Boston Naming Test. The student researcher undertook four years of sign language classes during pursuit of an undergraduate degree, and has a fluent understanding in American Sign Language.

Procedures of ASL for Active Living

ASL for Active Living was developed by the student researcher and is comprised of eight sessions in which participants participated in both educational and recreational therapy components in order to develop an understanding of another language. All participants that met the entrance criteria were included in the study. Demographic information as well as participant interests was used to tailor how the sessions were conducted. Appropriate adaptations were made as required for each participant. Participants engaged in ASL for Active Living three times per week for an hour, and lessons gradually increased in complexity.

During the sessions, the participants were provided a sign language book, finger-spelling flashcards, optional homework sheets, and a whiteboard and dry erase marker. All participants were encouraged to practice as frequently as possible at the end of the

sessions as well as to utilize the signs with their signing partners when at home or outside of the program. The activities used by the student researcher were designed to enhance the learning experience for each participant. The lesson plan table for all eight sessions is located in Appendix F. White board usage was promoted to ensure participants who were not fluent in spoken language or had difficulty with spoken language would not become frustrated when trying to speak during class. As an alternative they could write down answers, questions, or comments.

Each participant was taught how to perform the signs and engaged in recreational therapy-based activities to enhance the learning experience and increase rates of vocabulary retention. Each session began with a relevant educational lesson that focused on various areas such as: background information of sign language, how to communicate using the body, importance of health and body, emotions and how to convey emotions through sign language, as well as leisure and recreation. Participants interacted throughout the educational portion, and the student researcher further elaborated on topics for greater understanding as well as to establish relevance for each participant. A sample protocol for the educational lesson can be located in Appendix H.

After attention and relevance were established through the initial educational activity, participants briefly reviewed the vocabulary from the previous week and then began a game or activity that reinforced the learning and retention capabilities of all the participants. Sample protocols for the activities utilized for sessions can be located in Appendix G. Activities ranged from common games such as charades or hangman to more complex games such as Whiteboard scramble or Sign Bingo. These activities were

designed to increase confidence levels in relation to the ARCS model identified in Chapter 3.

Each session included either an introduction of new vocabulary or a review of the previous session's vocabulary. Partner groups were not only encouraged to engage in learning but to also teach other participants by reviewing the vocabulary from the previous week for the class. This increased the level of autonomy which expanded the learning experience and assisted in retention. All participants received assistance from the student researcher if needed and did not have to assist in reviewing vocabulary if uncomfortable. This was strictly optional and based solely on the participants' comfort levels.

During the first introduction session the student researcher discussed the optional final project that participants could complete. This project would have been substituted for a test as the program was designed to be fail-free in which every participant could succeed in one way or another. Because of the short amount of time to complete the project, participants opted against it as they did not feel they would finish or complete it adequately. Therefore, levels of improvement were identified through the increased complexity of the sessions and an activity called White Board Scramble, which is located in Appendix G. The student researcher was able to determine whether participants were improving or not through the use of this activity. At the completion of the project participants were awarded a Certificate of Completion for maintaining enrollment within the sessions. This certificate also reinforced the satisfaction component of the ARCS model.

Data Analysis

The pre- and post-tests for this group were analyzed utilizing standard single case report comparisons. The results of each participant were then examined individually utilizing the procedure described by Datillo, Gast, and Schleien (1993) as single-subject research. The data for four participants was collected and examined at pre- and post-test measures to determine whether this intervention created a positive change in depression, self-esteem, and satisfaction. The PHQ-9, Rosenberg Self-Esteem scale, participant evaluation of satisfaction, as well as researcher observations of engagement levels were analyzed to determine the effectiveness of the intervention. Because statistical analysis would prove greater inefficiency for this type of research, final results will be displayed in visual form. To show the effects of the intervention for each participant the data are presented as bar charts and graphs to provide a detailed visual summary for all components across the intervention period. Measurable differences between pre- and post-test results will be attributed to the intervention for each participant. Findings will be described in the final chapter.

CHAPTER V

TREATMENT OF THE DATA AND DISCUSSION

The primary objective for this study was to determine whether the ASL for Active Living is a feasible intervention for individuals with PPA. A pre-experimental design was used to answer the following questions: First, will an eight session RT intervention impact on symptoms of depression in individuals with mild memory loss and aphasia? Second, will participation in this intervention change levels of self-esteem? Third, to what extent will the older adult participants be able to learn and retain finger-spelling and vocabulary taught? Lastly, will participants be satisfied with this type of intervention?

A case study approach was used to describe the data for each participant. Participant demographics, actual examples of experiences, engagement levels, and assessment results represent the data obtained. Each participant's results were examined individually to determine whether the intervention led to changes in depression and self-esteem, and to evaluate overall satisfaction. The data collected is a mix of pre-post evaluations and qualitative data as the combined approach most effectively reflects the changes that occurred in a method that stimulates actual clinical practice. Preliminary results are presented in the form of four individual case studies. Future research will need to identify whether the changes are significant in a controlled trial with a larger sample size. The findings will be reported per participant as each person presented with unique diagnoses, experiences and changes over the course of the intervention period.

This intervention was conducted with four participants who all currently reside in a Continuing Care Retirement Community (CCRC) in North Carolina. All participants

were Caucasian females between 80-88 years of age. Participants were well educated reporting 16-24 years of education. Mrs. T attended with a partner Mrs. H and Mrs. A attended with her husband, Mr. J. Data and specific demographic information for these partners were not collected as the primary focus was on individuals experiencing memory loss and language impairments. Table 3 that follows provides a visual analysis of the demographic characteristics associated with the sample.

Table 3

Demographic Characteristics of the Sample (n=4)

<u>Demographics</u>	<u>Sample</u>
Age	
Mean	85.5 (80-88)
Gender	
Male	0 (0%)
Female	4 (100%)
Depression Diagnosis	
No	3 (75%)
Yes	1 (25%)
Dementia Diagnosis	
No	3 (75%)
Yes	1 (25%)
Aphasia	
No	1 (25%)
Yes	3 (75%)
Attendance with Partner	
No	2 (50%)
Yes	2 (50%)

Group Data Results

In order to determine whether the ASL for Active Living intervention was feasible as a recreational therapy program, pre- and post-test scores were examined on three levels to determine whether participants experienced a change in symptoms of depression, a change in self-esteem, and were satisfied with the experience. An examination of the depression scores for all participants revealed an average pre-test score of 4.75. At post-test the mean score for depression among all participants decreased to 2.25. Changes from pre- to post-scores indicate an average decrease of 2.5 points for the group in the area of depression. See Table 4 and Figure 2 that follow for visual presentation of pre- to post-test scores for depression for all participants.

Table 4

PHQ-9 Pre- and Post-test Scores for Each Participant

<u>Assessments</u>	<u>Participants</u>				<u>Mean Scores</u>
	Mrs. N	Mrs. T	Mrs. A	Mrs. B	Mean
Pre-test	4	0	9	6	4.75
Post-test	2	0	7	0	2.25

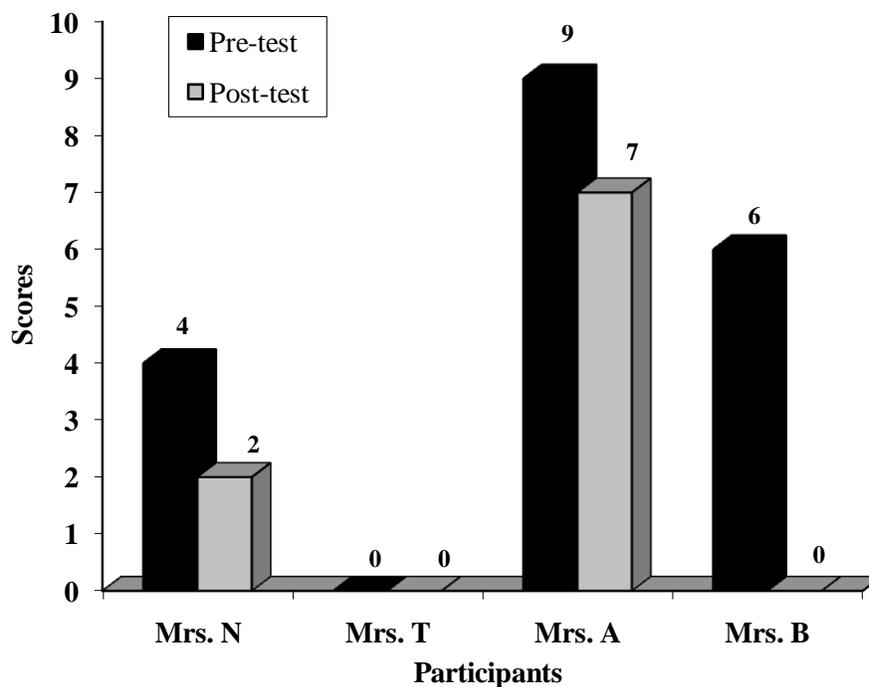


Figure 2. Pre- to post-test scores on the PHQ-9 Depression Scale for all participants.

The second question examined whether the ASL for Active Living program would have an impact on self-esteem. A higher score on levels of self-esteem indicate improved self-esteem. The Rosenberg Self-Esteem Scale was administered at pre- and post-test to identify any changes over the intervention period. In an examination of pre- and post-tests for all participants, self-esteem scores increased slightly by an average of 0.75. Only a slight increase in self-esteem was reported after eight sessions which indicates that a longer intervention period may be required for significant outcomes in the future. One participant showed a decrease in the level of self-esteem which may be due to poor attendance levels in the program. This will be discussed later in the individual case

section. Table 5 and Figure 3 that follow provide a visual analysis of the data for the sample.

Table 5

Participant Changes in Self-Esteem From Pre-test to Post-test

<u>Assessment</u>	<u>Participants</u>				<u>Mean</u> <u>Scores</u>
	Mrs. N	Mrs. T	Mrs. A	Mrs. B	Mean
Pre-test	20	23	17	20	20.5
Post-test	23	23	18	22	21.25

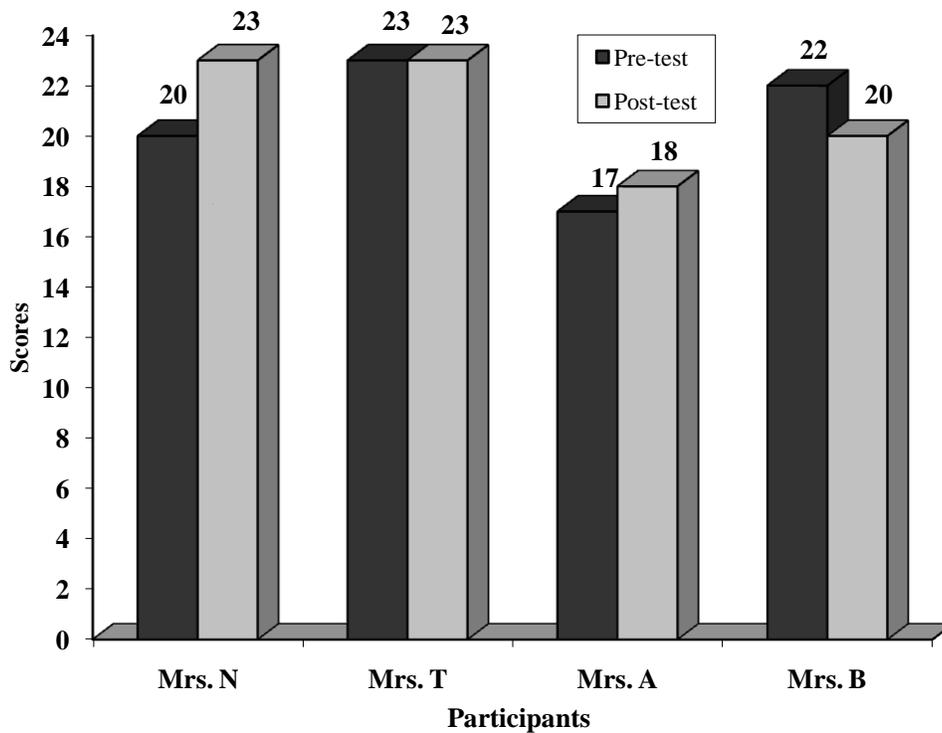


Figure 3. Pre- to post-test scores on the Rosenberg Self-Esteem Scale for all participants.

The third question examined whether older adults would be satisfied with this type of new intervention. Upon completion of the Participant Satisfaction Survey all participants reported the program met their learning needs, all reported they would recommend this program to others, and all reported they were highly satisfied with the experience. The four participants rated the program at an average of 9.25 on a satisfaction scale ranging from 1-10 with 10 being a perfect score. This would indicate as a group participants were highly satisfied overall with the new intervention. See Table 6 and Figure 4 that follow for visual presentation of the satisfaction ratings for each participant.

Table 6

Variables Indicating Satisfaction

<u>Satisfaction Survey Results</u>	<u>Sample</u>
Satisfaction Score %	92.5%
Needs Met	
No	0 (0%)
Yes	4 (100%)
Recommend Program to Others	
No	0 (0%)
Yes	4 (100%)
Satisfied with Experience	
No	0 (0%)
Yes	4 (100%)

Note. % = Percentage

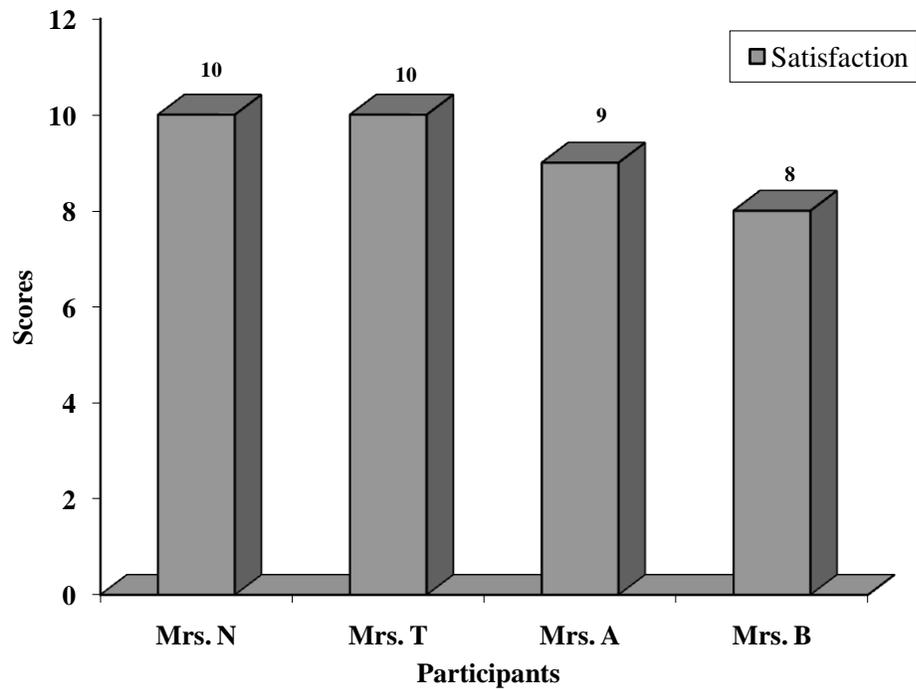


Figure 4. Satisfaction scores on a 1-10 scale as indicated by each participant on the Participant Satisfaction Survey.

Case Studies

Mrs. N

Mrs. N, an 88-year-old female with a chief complaint of memory loss plus arthritis and hypertension, currently lives independently in an apartment. Mrs. N did not need assistance in Instrumental Activities of Daily Living (IADL's) or Activities of Daily Living (ADL's), and was able to drive. She is highly educated with a Master's degree in Music and was interested in the program due to memory loss concerns. Mrs. N reported she wanted to participate in a program that would help cognitive functioning and thought learning sign language may be beneficial for both her brain and her arthritis. She is new

to the CCRC community; therefore, participation in groups also increased social engagement opportunities. She reports regular exercise and a healthy diet on her ASL for Active Living - Demographic Information sheet (Example located in Appendix C).

At baseline Mrs. N indicated a mild level of aphasia as examined by the BNT and a 29/30 on the MMSE which indicates a normal memory score. Scores did not reveal a major impairment in language or cognitive abilities, but did meet the initial entrance criteria for this study. Mrs. N was assessed with the PHQ-9 which indicated that a level of minor depression was present (score = 4). She scored 20 on the Rosenberg Self-Esteem Scale indicating a score that falls within a normal range for older adults. The Cornell-Brown Scale for Quality of Life and the Ohio Functional Assessment Battery for Leisure Motivation – Section E. were administered at baseline to determine current quality of life state, and to evaluate priorities for leisure engagement. Mrs. N received a +26 indicating a high quality of life and viewed her personal motivation to engage in recreational activities as physical enhancement, self-expression, social interaction, a sense of accomplishment, and most importantly intellectual enhancement on the Ohio Functional Battery. It is important to note the Ohio Functional Battery examined areas of motivation that contribute to individual engagement in recreation. As a result, individuals indicated which areas most reflected their motivation on a 1-4 scale with a four being always. Only threes and fours were indicated within the baseline data as highly motivating.

Mrs. N did not attend sessions with a partner but did work with Mrs. B for activities that required a partner. Mrs. N attended the first class which was primarily an

introduction to sign language, designed with “fun-facts” and learning how to finger-spell the alphabet. This session was researcher-facilitated, yet she was highly focused and clearly motivated with a 100% engagement level. As each session became increasingly more experiential, Mrs. N appeared to keep up with the activities and become more comfortable with the material and the group setting. She picked up the finger-spelling and vocabulary very quickly and reported that she was practicing everyday in preparation for the next session.

As sessions increased in complexity this researcher noticed Mrs. N continued to develop her sign language vocabulary. Intervention activities such as *White Board Scramble* (Appendix G) allowed for the evaluation of word retention as it is a vocabulary interpretation game. Mrs. N scored the highest in comparison to other participants with a demonstrated recognition of 39 vocabulary words after the first four sessions. Furthermore, she only missed one class as a result of a doctor’s appointment and received 100 % engagement levels for all sessions she attended. Observational data indicated she was active and highly engaged in all sessions. Mrs. N required little additional help to complete signs and often assisted other participants when they needed assistance. Although Mrs. N was hesitant to take part in the study due to arthritis in her hands she did not mention any problems during the intervention.

After completion of the program Mrs. N was re-assessed on the Rosenberg Self-Esteem Scale and the PHQ-9. The PHQ-9 score dropped two points from a four to a two indicating a decrease in depression symptoms. Her score on the Rosenberg Self-Esteem Scale increased from a 20 to 23 indicating an improvement in self-esteem.

Mrs. N also completed the Participant Satisfaction Survey which allowed for feedback and provided an indication of personal satisfaction. She rated the intervention as a 10 on a 1-10 scale (10 = best), she felt this program met her needs, would recommend this course to others, and was highly satisfied with the overall experience. In summary Mrs. N showed a two point decrease in symptoms of depression, an increase in self-esteem, and she was highly satisfied with the overall program. She was able to learn the finger-spelling and over 90% of the vocabulary taught in just eight sessions.

Mrs. T

Mrs. T, an 87-year-old female currently resides independently within the CCRC community. She was recommended for this research by the recreation therapy staff as a potential candidate for participation. Upon initial contact Mrs. T was very interested in the intervention and was eager to take part. Her primary diagnosis was Spasmodic Dysphonia (SD), which is a voice disorder caused by involuntary movements in one or more of the muscles in the vocal cords during speech. Mrs. T indicated this condition occurred suddenly and has caused communication difficulties for her since onset. She has tried numerous treatments including Botox injections into her vocal cords to relax the muscles. She reported this treatment caused her to choke when eating. As a result, Mrs. T was interested in alternative interventions for her communication problems. She has no formal diagnosis of depression or dementia. Mrs. T reports she is totally independent in IADL's and ADL's. She also reported that she maintains an active leisure lifestyle and attends routine fitness classes to sustain physical health.

Mrs. T's primary motivation for participating in the study was to develop an alternative communication method. Her MMSE was a 29/30 which indicates a memory score within normal ranges, yet still meets the entrance criteria for the study. Mrs. T's depression score showed no indication of depression (score = 0). Mrs. T however, did state, "I am losing my friends because of my voice. They find it very difficult to hear and understand me. It is very frustrating that no one really wants to talk to me anymore." At baseline Mrs. T scored a 23 on the Rosenberg Self-Esteem scale and indicated mild aphasia on the BNT. Furthermore, on the Cornell-Brown QOL scale Mrs. T received a +28 and expressed her primary motivations for engagement in leisure and recreation as physical enhancement, social interaction, sense of accomplishment, and intellectual enhancement as indicated as priorities on the Ohio Functional Battery Assessment – Section E.

Mrs. T began the first session highly motivated and engaged in the session activities. She received her flashcards and book early and as a result practiced signs and finger-spelling before the first session. During the first session, the researcher began with an activity asking each individual to work with a partner to identify an enjoyable recreational activity. This exercise was executed without sound, voice, or language. There was no requirement to use sign language as this was the opening session. The first time this activity was conducted Mrs. T picked the basic activity of walking, which requires very simple gesturing skills. After completion of the lesson which focused on how to use your body as a means of communication and incorporate body language, facial expressions, posture, and gestures the participants were then asked to pick another

activity and try again. Mrs. T appeared to become more confident in the second exercise as she chose a more complex activity to communicate. She demonstrated more visual facial expressions and enhanced body language. This exercise indicated a high level of understanding and retention of the material.

Throughout the sessions, as they began to progress in complexity, this researcher observed Mrs. T kept up very well and assisted her partner Mrs. H. She often volunteered to demonstrate in front of the group and her skills improved in both gesturing as a form of communication and sign language. She asked questions of the researcher and of her peers to ensure personal success. Her engagement levels were observed and reported as 100% for all eight sessions. Mrs. T attended every session. Her gradual progression and development of basic vocabulary and finger-spelling was outstanding as she was able to recite the full alphabet using finger-spelling, without the assistance of flashcards. She retained approximately 35 words as measured after four sessions by her score on the *White Board Scramble*. Mrs. T reported on several occasions that she was attempting to teach friends and family what she was learning throughout sessions. Finger-spelling was indicated as her first priority. By the end of the class it was evident that she had achieved an alternate level of communication that she could begin to further develop and teach her friends.

Mrs. T's post-tests did not indicate changes in depression or self-esteem. Since she had no depression and a high level of self-esteem at baseline it would have been difficult to indicate positive changes. On the Participant Satisfaction Survey Mrs. T rated the program a 10 on a (1-10 scale) and indicated that the intervention met her needs. She

reported that she would recommend this program to others, and she was highly satisfied with her experience. Her retention of the vocabulary and finger-spelling indicated that she could successfully learn parts of sign language.

Mrs. A

Mrs. A, an 80 year old female, also resides independently in the CCRC community. She lives with her husband, Mr. J, who served as her partner throughout the ASL for Active Living program. Mr. J. attended sessions if Mrs. A was unavailable due to doctors' appointments. Mrs. A had an existing diagnosis of Mild Cognitive Impairment (MCI) which she received three years ago. She currently takes cognitive enhancement medications (Aricept) as well as anti-depressants (Symbalta) for her previously diagnosed depression. She reports she is independent in all IADL's and ADL's, and drives and manages family finances. Mrs. A lives an active leisure lifestyle and exercises regularly as indicated on her demographic information sheet.

At baseline, Mrs. A received a score of 30/30 on her MMSE indicating a normal memory score but she met the entrance criteria based on her documented diagnosis. She scored nine on her PHQ-9 indicating evidence of depression. She also demonstrated moderate aphasia on the BNT, indicating a clinical need for the intervention. Mrs. A also scored 17 at baseline for the Rosenberg Self-Esteem Scale indicating a low normal level for self-esteem. Her Cornell-Brown QOL score totaled at a +21 which falls within a healthy/normal range for quality of life. Mrs. A's primary motivations for leisure and recreation are creative enhancement and a sense of accomplishment as indicated on the Ohio Functional Battery Assessment-Section E.

Mrs. A expressed interest in the program but was reluctant due to arthritis in her hands. She also questioned whether sign language would be beneficial for her to learn. Mrs. A seemed reluctant and skeptical at first upon initial entrance to the first session, yet her demeanor changed after the class began. Upon completion of the first activity in which participants introduced a recreational activity they enjoy doing to their partners and then to the group, this researcher noticed she began to immediately volunteer for the gesturing and demonstrating of other activities. In the first week when she arrived at the program, she was fairly reserved prior to the session starting but when the program began her demeanor and level of motivation appeared to change.

The skepticism lasted two sessions upon entrance of the program and after that there was noticeable improvement in demeanor, even when Mrs. A first entered the session. The researcher also observed and noted this participant walking around the CCRC with her finger-spelling flashcards and was observed practicing before the start of each session. Mr. J and Mrs. A reported they practice together and sign to each other using finger-spelling and some basic vocabulary when in their apartment. Mrs. A became more of a teacher after the first few sessions as her awareness of the language and her own capabilities to learn the material were developing. She began to encourage her husband, and even help him and the other participants if they had difficulties.

As sessions progressed in complexity, Mrs. A began to challenge herself and engaged in finger-spelling games without using flashcards. She demonstrated the ability to use the white board as a tool used to interpret what was finger-spelled to her. Very little assistance was needed from the researcher in either signing or the interpretation of finger-

spelling after the first few sessions. Mrs. A began to show observable emotion when gesturing and her actions were clear and concise.

Mrs. A's demonstrated improvements in the areas of retained signed vocabulary, depression, and self-esteem to help answer the proposed research questions. On the PHQ-9 she experienced a two point drop in levels of depression reducing her score from a nine to a seven. On the Rosenberg Self-Esteem Scale Mrs. A increased her self-esteem from a 17 to 18. After participation in the activity *White Board Scramble* Mrs. A identified approximately 25 vocabulary words she had learned and retained in four sessions. She also successfully executed finger-spelling using the entire alphabet without using the flashcards after the first four sessions. This finding indicates that despite a diagnosis of MCI it was still possible for this participant, with mild memory impairments, to successfully learn and retain information, specifically sign language.

Mrs. A also indicated positive feedback in her Participant Satisfaction Survey rating the intervention program a 9/10 (1-10 scale) and indicated that the intervention met her needs. She indicated that she would recommend this program to others, and was highly satisfied with her experience. Mrs. A received 100% engagement rating for all sessions she attended. She did miss one session due to a doctor's appointment. Mrs. A appeared to have overall success with this program.

Mrs. B

Mrs. B, an 87 year old female, resides independently in the CCRC community. She is a highly educated woman with a Master's degree in Counseling. Mrs. B expressed a chief complaint of memory loss and noted she experienced hypertension and arthritis. She has

adequate vision and hearing with the assistance of glasses and hearing aids. She requires the use of a walker and is independent in IADL's and ADL's. Mrs. B is active as she regularly attends exercise sessions and enjoys playing bridge and other games with her neighbors and friends within the community (as indicated within her Demographic Information sheet). She was interested in this study because she wants to keep her mind sharp.

At baseline assessment, Mrs. B scored a 28/30 on the MMSE indicating a normal range memory score and a six on the PHQ-9 indicating some symptoms of depression. She commented that most of her difficulties occur due to lack of sleep and poor concentration. Mrs. B scored a 22 on the Rosenberg Self-Esteem Scale indicating her self-esteem was within normal range. Her QOL assessment was scored as +23, which suggests a healthy QOL. Mrs. B had no indication of aphasia according to the BNT. Mrs. B indicated emotional release, physical enhancement, self-expression, social interaction enhancement, and sense of control as important to her leisure motivation. Although these were all noted as important factors for motivating her to engage in leisure opportunities, she included her top two priorities as a sense of accomplishment and intellectual enhancement on the Ohio Functional Battery – Section E. Mrs. B met the criteria for this study based on depression symptoms.

Mrs. B attended four sessions and missed four others due to medical appointments which included the first class. Despite missing the first session Mrs. B quickly caught up in session two and easily learned the finger-spelling with reliance on her flashcards. She attended sessions with the visual aids and mentioned that she was eager to get her “brain

working.” She had some difficulty picking up the signs due to missing the sessions in which they were introduced. The researcher noticed Mrs. B was excellent with gestures and showing emotions and therefore enjoyed the associated games played during each session.

Because Mrs. B was able to attend four sessions she required more assistance in performing signs and had a lower retention of vocabulary. With the help of her in-session partner (Mrs. N) and her visual aids Mrs. B did retain approximately 15 vocabulary words and memorized the hand-shapes for finger-spelling. She was most engaged in an activity called Sign Hangman as well as another activity called Beginning with the Ending (See protocols in Appendix G). Her finger-spelling abilities as well as interpretation of finger-spelling improved gradually over the eight sessions.

At post-test Mrs. B showed changes in both assessed areas. The Rosenberg Self-Esteem Scale score showed a two point decrease in self-esteem as her score changed from 22 to 20. Conversely, her depression score decreased by six points which indicated dramatic improvement. Mrs. B was satisfied with the program rating it as an 8/10. She indicated that she would recommend this program to others and that it met her needs. Her observed engagement levels were recorded as 100%. She was noted by this researcher as active and enjoying the sessions when in attendance. Her vocabulary retention over the two and a half week program was approximately 15 words. Although Mrs. B was only in attendance for half of the sessions she showed a remarkable decrease in depression. While her self-esteem score slightly dropped at post-test, it is possible her lack of routine attendance most likely contributed to that poor outcome. These findings indicate that

attendance may play a role in the changes of the variables from pre- to post-test, yet further testing would be required to successfully make those conclusions. Future studies should consider attendance as a variable of learning retention. Mrs. B retained 15 vocabulary words and demonstrated success in learning, retention, and interpretation of finger-spelling. Overall these case findings add support to the feasibility and efficacy of the intervention.

Summary

The purpose of this small scale intervention development study was to determine whether interactive sign language lessons could decrease depression in community-dwelling older adults with mild to moderate PPA. Four participants with varying diagnoses were recruited from a CCRC community in North Carolina to engage in eight interactive sign language sessions.

Participants were recommended to the researcher by the Recreation Therapy Department staff as potential residents who met the entrance criteria. None of the participants had a true diagnosis of PPA, although the sample contained various diagnoses that allowed for feasibility testing of the intervention sessions. At the pre-test participants were assessed using the PHQ-9 for depression, Rosenberg Self-Esteem Scale, Boston Naming Test, Cornell-Brown Scale for Quality of Life, as well as the Ohio Functional Battery for Leisure Motivation. Participants also completed a Demographic Information Sheet. At the post-test the PHQ-9, the Rosenberg Self-Esteem Scale, and a Participant Satisfaction Survey were used to answer the following research questions: First, will eight sessions of an RT intervention create a change in symptoms of depression

in older adults with mild memory changes and mild aphasia? Secondly, will participants experience a change in self-esteem? Third, to what extent will older adults be able to learn and retain vocabulary and finger-spelling in eight sessions? Lastly, will the participants will be satisfied with this new type of intervention?

The eight sessions consisted of interactive activities to increase concept retention, coping and educational lessons, as well as review which also contributed to the retention process. The four participants were encouraged to participate with a partner, although only two participants utilized this option. Each participant received a sign language book to aid in vocabulary development, finger-spelling flashcards, and a white-board and dry erase marker to eliminate frustration for participants with impaired spoken language. Participants were encouraged to come to all sessions although it was not mandatory.

Pre- and post-test scores of the four individual participants were compared to determine whether participants experienced changes in the areas of depression or self-esteem. Overall satisfaction with the program was measured. Results indicated that participants decreased an average of two points on the PHQ-9 depression which measured depression; increased 0.75 points on the Rosenberg Self-Esteem, and all felt the program met their needs. This recreational therapy intervention was rated and the average for the group was 9.25/10 indicating participants were highly satisfied. Engagement levels as observed by this researcher were found to be 100% for all participants in all session. This finding supports the idea that active learning using the ARCS model enables a quality learning experience that met the needs of this sample. Furthermore, vocabulary retention was informally assessed by the activity White Board Scramble which indicated

participants learned and retained an approximate average 32 vocabulary words over an eight session intervention period.

Discussion

The purpose of this section is to discuss the results as well as implications of this sign language intervention for the field of recreation therapy. This section will include elaboration of the major findings as well as limitations of this study.

This study indicated trends that have assisted the researcher in answering basic feasibility questions. Study participants as a group showed a 2.5 point reduction in depression from pre- to post-test after eight intervention sessions, showed slight increase (0.75) in self-esteem, and participants learned and retained an approximate average of 32 words, and were highly satisfied with the overall program. The most significant reduction in symptoms of depression was found in Mrs. B, who showed a six point decrease. Depression was the primary area of focus for this study, as the intervention was developed with the goal of reducing or eliminating depression in individuals with PPA. Although participants within the PPA population could not be identified within the time frame of this thesis study, participants all experienced positive results in a relatively short amount of time. Although the self-esteem results were not as remarkable, they were still positive as they indicated an average increase of 0.75. It is important to note that increase in self-esteem would require a longer intervention period to experience a noticeable change.

Completion of the Satisfaction Survey not only allowed for participant evaluation of the program, but also revealed high overall satisfaction regarding this recreational therapy

intervention. All participants were included in the Satisfaction Survey to ensure all feedback was identified. All participants and partners rated the ASL for Active Living Program at an average of 9.25 on a 1-10 scale. Participants indicated they were overall highly satisfied at the completion of the program and that their needs were met. All participants and partners also reported they would recommend this program to others. The satisfaction rating provided this researcher with important feedback that would allow for the future development of the intervention as a controlled clinical trial.

The results of the study also reinforce the literature from Fitzsimmons and Buettner's (2003; 2009) Health Promotions study regarding older adults with memory impairments having the capabilities to learn new information. Informal assessments of vocabulary retention indicated that an average of 32 vocabulary words could be learned in just eight sessions. As mentioned in Chapter 2, researchers have identified that information can be learned and retained if it is of relevance and importance to the individual (Fitzsimmons & Buettner, 2003). These interactive sign language sessions were conducted in a way that would increase attention and relevance in order to achieve confidence and satisfaction, in accordance with the ARCS model (Keller, 1983). By following the ARCS model and developing interventions that are engaging, interactive, and relevant to the individual the intervention provided for a level of success. Future research on a larger scale, with a control group and larger sample size is required to test the full impact and generalizability of this study.

Implications

The preliminary success of this small developmental intervention study provides the first step in the development of an experimental study of recreational therapy for treatment of depression in PPA. Once a larger controlled study shows the efficacy of this recreational therapy intervention program it could provide the field with a new venue for services. With the aging baby boomers living longer and memory loss being diagnosed earlier there is a significant amount of time for this intervention to improve quality of life. Since there has been a significant increase in the population of individuals in the 65-84 range as well as the 85+ range (Spirduso et al. 2005) these are the types of interventions that have been identified as critical in healthcare reform. It is crucial to identify new interventions for sub-population and dementia diagnoses. Future testing of this intervention may show efficacy for many types of dementing illnesses or even prevention in dementia in persons with Mild Cognitive Impairment.

Efficacy-based intervention studies have been conducted and tested for individuals with cognitive impairments and depression. Specifically, Fitzsimmons (2002) examined the wheel-chair bike intervention program for individuals with dementia and depression and noted significant results in only two weeks of treatment. Although this study has provided significant results, further research is needed in RT that focuses on other problems. This active sign language intervention has the potential to serve as an effective treatment option for persons with PPA or mild memory changes and signs of mild aphasia. It may also provide greater co-treatment opportunities with other allied health professions, specifically speech therapy (ST). Integrating the two approaches of RT and

ST may possibly lead to more successful treatment and improved quality of care for older adults especially with co-existing depression and aphasia. Future studies are necessary to understand and examine the full effects of this intervention, as well to determine whether this intervention would, in fact, truly benefit individuals with PPA. Further examination of other variables such as self-esteem, quality of life, and learning capabilities of individuals with memory impairments should be included in greater depth within a larger sample.

Limitations

Several limitations prevent these findings from being generalized to the PPA population. First, a small local convenience sample of participants with normal range MMSE scores and aphasia was used, none of whom had a true PPA diagnosis. All participants were located within the CCRC and all data was collected for older white females of upper economic status. Therefore, a diverse study with a larger sample of community-dwelling older adults would help improve generalizability. Secondly, there was no control group used in the study thus now comparisons could be made. Third, eight sessions may not be a sufficient amount of time to determine if this intervention impacts on self-esteem. In order to be successful, future studies should examine intervention outcomes at several time points to evaluate the long-term impact and changes over the course of time. There was a lack of follow-up to determine long-term retention of vocabulary and finger-spelling.

It is unknown whether these participants would be able to continue practicing and increasing their sign language knowledge base at the conclusion of the intervention.

Therefore long-term follow-up may be beneficial in future studies to determine whether the activities provided as well as the dosing are adequate factors for long-term retention. Furthermore, because there were no individuals with PPA it is difficult to identify whether this intervention would actually benefit this diagnostic group. Further studies must incorporate individuals with this diagnosed condition to report whether this intervention would lead to successful outcomes. Lastly, the use of self-report on the measurement scales may reduce the accuracy of scores. Participants may not fully disclose their level of depression, self-esteem, or quality of life due to fear of stigmatization. All of these factors should be carefully controlled in future research using this now fully developed intervention.

Conclusion

This small feasibility study was not designed or powered to test hypotheses. It was designed to flesh out design issues and measure possible outcomes for individuals with mild memory loss, aphasia, and depression. The findings, based on four cases, are promising and may lead the field of recreation therapy to co-treatment with speech therapy, advanced practice in early-stage dementia, and a large scale clinical trial. The ASL for Active Living Program appears to have the potential to reduce depression in older adults, and in turn improve their quality of life.

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Appendix A

Cover Letter

February 12, 2010

To Whom It May Concern:

We are writing to ask if your clinical program would allow us to post our research study recruitment flyer. We are studying whether interactive sign language lessons can increase social engagement with others as well as decrease potential levels of depression in individuals with mild to moderate Primary Progressive Aphasia or Mild Cognitive Impairment with language impairments. Currently, this is a pilot intervention-development study that will be conducted as thesis research, with the permission of the UNCG Institutional Review Board, in which we are providing sign language lessons, methods for coping skills, and recreation-therapy based interventions to individuals who meet study criteria. Limited research has been conducted for interventions among this population, therefore assessments and intervention protocols were designed to determine overall success of the intervention.

We are recruiting English speaking adults between the ages of 50 and 70 who already have identified a diagnosis of Primary Progressive Aphasia or Mild Cognitive Impairment with speech deficits. They will receive a free memory screening; quality of life, leisure motivation, and depression assessments; and a fluency naming assessment scored by a Certified Speech Language Pathologist. The study will take place twice/week for 1 hour sessions. Participants will be encouraged to attend with a partner (spouse, friend, family member, neighbor, etc.).

In order for us to post our flyer at [REDACTED], our Institutional Review Board (IRB) requires that we submit a notice of support from your clinical practice. I've enclosed a sample support letter and a copy of the IRB approval letter allowing us to engage in this research. If you agree to our request, you may copy the support letter (or adapt it) and return it in the enclosed self-addressed stamped envelope. Upon receipt of your support letter, we will visit your clinical practice to post the flyer. I've enclosed an example of the flyer for your review.

Please do not hesitate to contact us if you have any questions or concerns. I am a graduate student at UNCG in the Department of Recreation, Tourism, and Hospitality Management, focusing in Recreation Therapy. My email address is alsardin@uncg.edu and my telephone number is [REDACTED].

Thank you for your time and attention.

Regards,

Angie Sardina, B.S.
Graduate Student at the University of North Carolina at Greensboro

Appendix B
Consent Form

UNIVERSITY OF NORTH CAROLINA AT GREENSBORO
CONSENT TO ACT AS A HUMAN PARTICIPANT: LONG FORM

Project Title: A Recreation Therapy Twist to Sign Language: An Intervention for Primary Progressive Aphasia

Project Director: Angela Sardina, BS, Student Researcher

Participant's Name: _____

What is the study about?

This is a research project to help scientists learn more about helping people over 50 years of age with Primary Progressive Aphasia or Mild Cognitive Impairment with language impairments. The use of interactive recreation-therapy based sign language interventions have been developed and will be utilized for each session.

Why are you asking me?

We are asking you to take part because you are over the age of 50 with Primary Progressive Aphasia or Mild Cognitive Impairment with language impairments.

What will you ask me to do if I agree to be in the study?

The UNCG student researcher will provide you with free assessments and two and a half weeks of classes. These are experimental and it is hoped that you will benefit from them; however, this cannot be guaranteed. These classes have been developed to teach people with PPA sign language. Sign language may help people with PPA to better communicate with others.. Each week you will have 3-hours of class time, 1 hour three times/week, with optional homework to complete to maximize the learning experience. We will try to schedule the classes at a convenient time for you. All participants will participate with a partner of their choice (spouse, child, grandchild, friend, neighbor, etc) and both will receive fun and interactive sign language lessons as well as supportive information relevant to participants. During the study we will ask you to complete some surveys about your memory, your mood, and your quality of life. These should take approximately one and a half hours to complete and will be completed prior to-and at the conclusion of the program. We will monitor your participation levels during each session. You may refuse or withdraw at any time if you don't like the program. If you have any questions or concerns you can contact Angie Sardina, BS, Student Researcher at [REDACTED].

Is there any audio/video recording?

There will not be any audio or video recording during the study.

What are the dangers to me?

The Institutional Review Board at the University of North Carolina at Greensboro has determined that participation in this study poses minimal risks to participants. Some people may feel slightly embarrassed or ashamed to be part of Primary Progressive Aphasia study and the student researcher will be happy to talk with you at any time if you feel this way. To protect your confidentiality, all data will be coded.

If you have any concerns about your rights, how you are being treated or if you have questions, want more information or have suggestions, please contact Eric Allen in the Office of Research Compliance at UNCG at (336) 256-1482. Questions, concerns or complaints about this project or benefits or risks associated with being in this study can be answered by Angie Sardina who may be contacted at [REDACTED] (or by email: alsardin@uncg.edu).

Are there any benefits to me for taking part in this research study?

Participants may become more active, meet others with similar problems, learn therapeutic techniques to help with symptoms, and improve on measures of mood and communication abilities. Some people may not experience any direct benefits from participation. This study will determine if these interventions produce direct benefits to participants.

Are there any benefits to society as a result of me taking part in this research?

The program tested in this study may benefit others with Primary Progressive Aphasia in the future if they are successful.

Will I get paid for being in the study? Will it cost me anything?

There are no costs to you or payments made for participating in this study.

How will you keep my information confidential?

All information obtained in this study is strictly confidential unless disclosure is required by law. Forms with research participants' personal information will be shredded after the two and a half week intervention period. All data files will have de-identified coded information only. Your name will not be on any forms and you will be given a code number to protect your privacy. The data collected will be stored in a locked file cabinet in the Student Researcher's Advisor's UNCG office and computerized information will be password protected. The consent forms will be kept for three years after the closure of the study then shredded.

What if I want to leave the study?

You have the right to refuse to participate in any session or to withdraw from the study at any time, without penalty. If you do withdraw, it will not affect you in any way. If you choose to withdraw, you may request that any of your data which has been collected be destroyed unless it is in a de-identifiable state.

What about new information/changes in the study?

If significant new information relating to the study becomes available which may relate to your willingness to continue to participate, this information will be provided to you.

Voluntary Consent by Participant:

By signing this consent form you are agreeing that you read, or it has been read to you, and you fully understand the contents of this document and are openly willing consent to take part in this study. All of your questions concerning this study have been answered.

By signing this form, you are agreeing that you are 18 years of age or older and are agreeing to participate, or have the individual specified above as a participant participate, in this study described to you by Angie Sardina

Signature: _____ Date: _____

(If needed) Legal Guardian:

_____ Date: _____

Appendix C

Demographic Information Sheet

ASL for Active Living – Demographic Information

Subject #: _____ **First Name:** _____ **Site:** _____ **Gender:** F M

DOB: _____ **Race:** _____ **Ethnicity:** _____

Language: _____ **Type of Housing:** Home Condo Apartment AL

Lives with Friends/Relatives (Name and Number): _____

Highest Education Completed: _____ **Past Occupation:** _____

Dementia Dx: Yes No **Type:** _____ **When Dx:** _____

Cognitive Medication: Yes No **Type:** _____

Depression Dx: Yes No **Anti-depressant:** _____

Other Diagnoses such as High Blood Pressure, Diabetes. Please List.

Non-Medication Allergies (Latex, Peanuts, Bee-stings) _____

Vision: Adequate Inadequate **Hearing:** Adequate Inadequate

Speech: Impaired Unimpaired

Circle Glasses Hearing Aids Oxygen Other: _____

Any assistive device: (Cane, wheelchair, walker, etc) _____

ADL's: Ambulation: Self 1/Assist 2/Assist Self Propel W/C Electric W/C

Transfer: Self 1/Assist 2/Assist **Hygiene/Bathing:** Self With Assist

Dressing: Self With Assist **Toilet:** Self With Assist

IADL's: Cooking: Self Occasionally No longer cook Never cooked

Driving: Self Occasionally No longer drive Never drove

Finances: Self Occasionally No longer manage finances Never managed finances

Housekeeping: Self Occasionally No longer do housekeeping Never did
housekeeping

Medication Management: Self With Assist

Exercise 3x/week for 30 minutes: Yes No **Type:** _____

Leisure Interests:

Appendix D

ASL for Active Living Engagement Forms

ASL for Active Living Session Engagement

Today's Date: _____ Time: AM PM Group Size: _____

Session #: _____ First Name: _____

Subject Code: _____ Facilitator: _____

Time spent in minutes: _____ Engagement %: _____ Did Not Attend

Participation: Mark **one** below.

- 0 = Dozing: Eyes closed.
- 1 = Refused: Unwilling to participate.
- 2 = Null: Physically inactive, eyes opened but not focused on a particular event or person, no purposeful activity, no interest in what others are doing.
- 3 = Passive: Paying attention to the activity, others participating in the activity, or the interventionist, or commenting on the activity while not directly engaged in the activity.
- 4 = Active: Physically or verbally engaging in the activity.

Encouragement needed to attempt the task: Mark **one** option below.

- 0 = Normal: Instructions given than activity performed.
- 1 = Some Additional: Required additional prompting to try doing the task.
- 2 = Much Needed: Required urging to try doing the task.

Observed/Verbalized Behavior: Mark **all** that apply.

- 0 = Discomfort: Complains of pain.
- 1 = Sleepy: Yawning, drooping eyes, verbally stating tired.
- 2 = Frustrated: Stating activities too difficult, pushing items away.
- 3 = Bored/Indifferent: Stating too easy, sitting passive.

- 4 = Did not like: Verbally stated they did not like doing the activities.
- 5 = Weepy: Crying, sobbing, verbalizing sadness.
- 6 = Restless, anxious, agitated: Motor and/or verbal restlessness, argumentative, irritable, aggressive, fearful.
- 7 = Suspicious, paranoid: Irrational fears or thoughts, apprehensive, distrustful, unreasonable.
- 8 = Enjoyed: Verbally stated pleasure or laughed, smiled.

Appendix E

Participant Satisfaction Survey

ASL for Active Living

Participant Satisfaction Survey

Thank you for your participation in the ASL for Active Living Program. Please take a few minutes to fill out this questionnaire regarding your experience with this program. All feedback is greatly appreciated.

1. Please rate this program on a scale of 1-10 (10=best)

1 2 3 4 5 6 7 8 9 10

Best

Worst

2. What did you enjoy about this experience?

3. Do you have any suggestions that would contribute to the improvement of this program?

4. Did this program meet your learning needs? Yes No

5. Would you recommend this program to others? Yes No

6. Are you overall satisfied with this experience? Yes No

Appendix F

Lesson Plan Table

Educational Lesson	Activities	Vocabulary Word Theme
1. Introduction to Sign Language	Silent Ice Breaker Introduce Finger-spelling	None
2. Introduce Key Components of Sign Language	1. Charades using key components of sign language.	Possessive words (I, Me, Mine), manners (Please, thank you...), Priority words (bathroom, water, drink...)
3. Conveying Emotions and Feelings	1. "Tour of Emotions" worksheets	Emotions and feelings
4. No Educational Lesson - Work on Finger-spelling	Forward Alphabet, Back-word alphabet Sign-Hangman	Need-based (Can't remember, have, need...)
5. Importance of Health and Body Signs	1. White-board Scramble	Health and Body
6. Review Leisure and Recreation	"Introduce your Leisure" Finger-spelling Review	Recreation and Leisure
7. No Educational Lesson - Review Finger-spelling and Vocabulary	Beginning with the Ending White-Board Scramble	Recreation and Leisure
8. No educational Lesson - Review Finger-spelling and Vocabulary	Sign BINGO and Sign Hangman OR... Presentation of Optional Family Picture Book Project	None

Appendix G
Sample Protocols

Beginning with the Ending Protocol
Sign Hangman Protocol
White Board Scramble Protocol

Finger-spelling

Protocol – Beginning with the Ending

This program is designed to increase ability to utilize and understand finger-spelling.

Staff Requirement: 1 Recreation Therapist, 1 student, or other health care professional.

Entrance Criteria: Symptoms of mild to moderate aphasia as a result of Primary Progressive Aphasia or Mild Cognitive Impairment, mild to moderate depression, and/or emotional distress.

Exit Criteria: Participant no longer enjoys the participating in the program, or the participant develops a full understanding of signing the alphabet.

Group Size: 2-6 participants.

Duration: 10 – 15 minutes

Safety Considerations

Environmental Risks: No specific risks identified.

Client Risk: No specific risks.

Facility and Equipment Required

Facility: A comfortable setting with limited background noise.

Equipment: Finger-spelling picture flashcards.

Method

- Gather clients into area in which intervention will be conducted.
- The group will sit in a circle so that everyone is able to see each other.
- The student leader will begin the game by finger-spelling any word they want.
- The person to the left of the leader will have to recognize the word finger-spelled and may either say it out loud or use the white board to write it down.
- Once they have correctly recognized the word that was finger-spelled, they must take the last letter of the word and create a new word from that letter.
 - a. For example: Student leader fingerspells cat.
 - i. The next person will say or write “cat”, and then fingerspell a word that starts with “t” (i.e., today)
 - ii. The next person will say or write “today”, and then fingerspell another word but this time the word starts with a “y” (i.e. yell).

- Participants may utilize their flashcards to help them figure out the word that is being signed, and may ask for the student leader's help if necessary.
- Participants will also be able to use flashcards when they are signing to other participants.

Possible Client Objectives:

1. Increase in socialization.
2. Working to increase or maintain function in motor skills.
3. Increasing comprehension of finger-spelling.
4. Increase in hand-eye coordination
5. Work on following-directions.
6. Develop and maintain attention span.
7. Decrease levels of depression
8. Decrease in emotional distress.

Finger-spelling

Protocol – Sign Hangman

This program is designed to utilize finger-spelling through the use of hangman, in order to practice finger-spelling, increase recall abilities, and to with motor skills.

Staff Requirement: 1 Recreation Therapist, 1 student, or other health care professional.

Entrance Criteria: Symptoms of mild to moderate aphasia as a result of Primary Progressive Aphasia or Mild Cognitive Impairment, mild to moderate depression, and/or emotional distress.

Exit Criteria: Participant no longer enjoys the participating in the program, or the participant develops a full understanding of signing the alphabet.

Group Size: 2-6 participants.

Duration: 15-20 minutes in length.

Safety Considerations

Environmental Risks: No specific risks identified.

Client Risk: No specific risks.

Facility and Equipment Required

Facility: A comfortable setting with limited background noise.

Equipment: Tables and chairs, a large whiteboard, dry erase markers, an eraser, and flashcards for participants to reference.

Method

- Have blank lines written out on board with available letters at the bottom to reduce re-guessing. Also have hangman drawn onto whiteboard before participants arrive to save time.
- Gather clients into area in which intervention will be conducted.
- Student conducting intervention and will explain that each person will try to work individually, but may ask partner/caregiver for help identifying signs.
- Student will encourage participants and their caregivers to use their flashcards if they do not know how to sign a letter.
- The student will begin with one individual and move clock-wise or counter-clockwise with each person guessing one letter through finger-spelling.

- If the student identifies the letter as part of the phrase, student must write the letter in the appropriate spot/s, and then erase the letter from list of available letters to guess.
- If a letter that is not in the phrase is guessed, the student leading the program will draw a body part, starting from the head down, and will erase the letter from the list of available letters.
- Student will encourage participants to continue guessing until the phrase is complete. Participants/caregivers will not have opportunity to guess the phrase, as the purpose is to increase abilities in finger-spelling.

Possible Client Objectives:

1. Increase in socialization.
2. Increase in body awareness and ability to communicate using non-spoken language.
3. Increasing and further development of problem-solving skills.
4. Increase in reasoning skills.
5. Increase in decision-making skills.
6. Work on improving or maintaining function of motor skills.
7. Decrease levels of depression through increased socialization.
8. Decrease in emotional distress.

Vocabulary

Protocol– White Board Scramble

This intervention is designed to help participants develop a greater understanding and comprehension of need-based and leisure based vocabulary.

Staff Requirement: 1 Recreation Therapist, 1 student, or other health care professional.

Entrance Criteria: Symptoms of mild to moderate aphasia as a result of Primary Progressive Aphasia or Mild Cognitive Impairment, mild to moderate depression, and/or emotional distress.

Exit Criteria: Participant no longer enjoys the program, or participant fully understands vocabulary words presented.

Group Size: 2-6 participants.

Duration: 15 - 20 minutes in length.

Safety Considerations

Environmental Risks: No specific risks identified.

Client Risk: No specific risks identified.

Facility and Equipment Required

Facility: A comfortable setting with limited background noise.

Equipment: Tables and chairs, white boards, dry erase markers, erasers or paper towels.

Method

- Gather clients into area in which intervention will be conducted.
- Student leader will have a piece of paper with a list of all the vocabulary words that participants should be familiar with.
- Student leader will instruct participants to get out their dry erase boards, markers, and erasers.
- Student leader will sign a vocabulary word two times, slowly.
- Then each participant will have to write down as quickly as possible, what they think the word is that is being signed.

- After they have written down the word they will hold up the whiteboard so student leader can tell them if they are right or wrong.
- Participants will keep trying until someone guesses the correct answer.
- Student leader may attempt gestures or facial expressions if participants have trouble guessing the word being signed.
- This is a race, so the first person to get the vocabulary correct will receive a point.
- The person with the most points at the end of the game will be the winner.

Possible Client Objectives:

1. Increase in level of mastery of vocabulary.
2. Working on ability to recognize visual signs and apply it to the written word.
3. Increase in reasoning.
4. Increase in attention span.
5. Increase in motor skill functions.
6. Decrease levels of depression through increased mastery of signs.
7. Decrease in emotional distress.

Appendix H
Educational Lesson

Sign Language Lesson 1

Student Leader: Angie Sardina

Facts about Sign Language:

- 1) No one form of sign language is universal. For example, British Sign Language is different than American Sign Language (ASL).
- 2) American Sign Language was first developed around 1817, after the first American school for the deaf opened in Connecticut.
- 3) Even though ASL is used in America, it is a language completely separate from English. It contains all the basic features a language needs to function on its own--it has its own rules for grammar, punctuation, and sentence order.
- 4) ASL is the 4th most common language in the U.S.

Key Elements to using Sign Language:

When using even basic signs, there are ways to express what you want to say:

- 1) Using basic signs
- 2) Body Language
- 3) Facial Expressions

Helpful hints on how to sign:

All signs have 3 basic parts:

- a. The shape of the hand
- b. The place where the sign is made
- c. The way the hand moves.

The hand you write with is your dominant hand. This is the hand you will fingerspell with and do your one-handed signs with.

How will it help you?

- 1) Practicing sign language will help you maintain or improve gross motor and fine motor skills.
- 2) It is an alternate means of communication that uses many methods to convey visual communication.
- 3) It will help you to increase your body awareness for better communication.

For further learning practice the ASL Alphabet:

